

# ENGAGING PATIENTS IN PATIENT SAFETY

## A CANADIAN GUIDE

Persistent  
Active  
ENGAGEMENT

Patient  
Safety

*The Engaging Patients in Patient Safety – a Canadian Guide (Guide)* was developed by the Canadian Patient Safety Institute, the Atlantic Health Quality and Patient Safety Collaborative, Health Quality Ontario and Patients for Patient Safety Canada in collaboration with an expert Action Team representing 16 organizations who are recognized leaders in patient engagement and patient safety. Visit our [website](#) to read more.

The Guide and complementary resources on [www.patientsafetyinstitute.ca/engagingpatients](http://www.patientsafetyinstitute.ca/engagingpatients) will be regularly updated and refined as new evidence emerges and new content is developed. Visit and bookmark the page above to ensure you are accessing the most up-to-date version.



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# Introduction: Partnering for safer healthcare

## Message from the authors

In recent decades, evidence has emerged that demonstrates when healthcare providers work closely with patients and their families, the healthcare system is safer, and patients have better experiences and health outcomes. Engagement with patients and families includes program and service design and delivery as well as monitoring, evaluating, policy and priority setting, and governance.

Engagement work is not easy and often may be uncomfortable at first. Providers may need to let go of control, change behaviours to actively listen to what patients are saying, and take additional time to understand the patient perspective. It may require more effective ways to brainstorm ideas together, build trust, and incorporate many different perspectives. Patients may need to participate more actively in decisions about their care. Leaders must support all this work by revising practices to embed patient engagement in their procedures, policies, and structures. Finding innovative ways to work together will benefit everyone.

We invite you to join us in advancing engagement by making healthcare safer.

Our deep belief in the power of partnership is inspired by the publication, *Engaging Patients in Patient Safety – a Canadian Guide*. It is written by patients, providers and leaders *for* patients, providers and leaders. We trust that you will find the information in this guide useful. It demonstrates our joint commitment to achieving safe and quality healthcare in Canada.

## Who is this guide for?

The guide is for anyone involved with patient safety and interested in engagement, including:

- Patients and families interested in how to partner in their own care to ensure safety
- Patient partners interested in how to help improve patient safety
- Providers interested in creating collaborative care relationships with patients and families
- Managers and leaders responsible for patient engagement, patient safety, and/or quality improvement
- Anyone else interested in partnering with patients to develop care programs and systems

While the guide focuses primarily on patient safety, many engagement practices apply to other areas, including quality, research, and education. The guide is designed to support patient engagement across the healthcare sector.

## What is the purpose of the guide?

The purpose of the guide is to help patients and families, providers and leaders work more effectively together to improve patient safety. The guide is an extensive resource that is based on evidence and leading practices.

## What is included in the guide?

- Evidence-based guidance
- Practical patient engagement practices
- Consolidated information, resources, and tools
- Supporting evidence and examples from across Canada
- Experiences from patients and families, providers, and leaders
- Probing questions about how to strengthen current approaches
- Strategies and policies to meet standards and organizational practice requirements

## How was the guide developed and updated?

The [National Patient Safety Consortium](#), a group of more than 50 organizations, established the [Integrated Patient Safety Action Plan](#), a shared action plan for safer healthcare. One of the plan's guiding principles is patient engagement, and one of the shared actions is a comprehensive guide for patient engagement based on evidence and best practices.

The [Canadian Patient Safety Institute \(CPSI\)](#), a national organization established by Health Canada to improve patient safety and quality in the Canadian healthcare system, led the work on the guide. The Canadian Patient Safety Institute, along with the Atlantic Health Quality and Patient Safety Collaborative, Patients for Patient Safety Canada, and Health Quality Ontario provided leadership and funding to develop the guide. Beginning in 2016, the Canadian Patient Safety Institute brought together patients, government, and organizations responsible for improving patient safety and quality at the national or provincial level, to form an Action Team to help develop the guide.

The Action Team included:

- [Accreditation Canada – Health Standards Organization](#)
- [Alberta Health Services](#)
- [Atlantic Health Quality and Patient Safety Collaborative](#)
- [B.C. Patient Safety and Quality Council](#)
- [Canadian Foundation for Healthcare Improvement](#)
- [Canadian Patient Safety Institute](#)
- [Centre of Excellence on Partnership with Patients and the Public](#)
- [HealthCareCAN](#)
- [Health Quality Council of Alberta](#)
- [Health Quality Ontario](#)
- [IMAGINE Citizens Collaborating for Health](#)
- [Manitoba Institute for Patient Safety](#)
- [Manitoba Health, Seniors and Active Living](#)
- [Ontario Ministry of Health and Long-Term Care](#)
- [Ontario Hospital Association](#)
- [Patients for Patient Safety Canada](#)
- [Saskatchewan Health Quality Council](#)
- [University Health Network](#)
- [University of Montreal](#)

A consultant team (One World Inc.) supported the Action Team's work by conducting an environmental scan to identify current evidence, leading, and emerging practices, and by drafting the content of the guide. The environmental scan offered examples of patient engagement in patient safety and quality, a targeted review of academic literature, a web scan, and interviews with key informants in the field.

Forty patients and providers from across the country participated in focus groups to help develop the guide's scope and content, including feedback on drafts. Ten patients and providers also participated in a usability pilot to validate the format and provide ideas on how to make the guide easier to use. Learn more [online](#).



Because patient engagement evidence and practice are continuously emerging, the guide was designed as an evergreen resource that is regularly updated and refined.

The first edition of the Guide was launched in 2017, the second edition in 2018 and the third edition in 2019. The 2018 and 2019 revisions were based on a quick review of the literature and leading practices, and in consultation with the Action Team.



Because of the key role accreditation plays in establishing patient engagement as a core feature of healthcare, the Guide is closely aligned with the standards established by the Health Standards Organization (HSO) / Accreditation Canada. Throughout the Guide the points of alignment are indicated by the HSO logo.

Please bookmark the website hosting the Guide as it includes additional information that complements this pdf document. The website is updated more frequently.

To contribute to the guide (e.g., with resources, leading practices, potential topics), or to be the first to know about updates, email: [patients@cpsi-icsp.ca](mailto:patients@cpsi-icsp.ca).

Complementary resources, including the Canadian Patient Engagement Network and the Canadian Foundation for Healthcare Improvement's Patient Engagement Resource Hub, are available [online](#).



# Engaging patients as partners



# 1. Engaging patients as partners

“The vision is not of staff striving to engage patients in ever more meaningful ways, but of patients and staff having collective ownership of efforts to improve their shared healthcare services; power residing not in any stakeholder group, but within the process of co-production/co-design.”<sup>1</sup>

Patients, providers, leaders, researchers, and policy makers now agree that engaging patients and families is essential to safe care. Partnering with patients shows respect, values their insights and experience, and empowers them to take an active role in their care. Many organizations, including hospitals, home and community care, long-term care, and primary care facilities are making great strides towards patient engagement, but they are still learning how to do this work collaboratively.

This chapter summarizes the benefits and impact, current state, challenges, and enablers to setting up and embedding patient engagement in an organization.



## Key Definitions

**Patient:** includes client, resident, person, individual, etc. and refers to those most impacted.

**Person (Patient, family) Centred Care:** an approach to care where patients and healthcare professionals partner to:<sup>2</sup>

- Give patients a voice in the design and delivery of the care and services they receive
- Allow patients to be proactive in their healthcare journey for better health outcome; and
- Improve the experience of patients

**People-centred care:** an approach to care that consciously adopts individuals’, carers’, families’ and communities’ perspectives as participants in, and beneficiaries of, trusted health systems that are organized around the comprehensive needs of people rather than individual diseases, and respects their preferences. People-centred care is broader than patient and person-centred care, encompassing not only clinical encounters, but also including attention to the health of people in their communities and their crucial role in shaping health policy and health services.<sup>1</sup>

**Patient engagement:** an approach to involve patients, families, and/or patient partners in:<sup>1</sup>

- Their own healthcare
- The design, delivery, evaluation of health services
- A way that fits their circumstances

Patients’ experiential knowledge is recognized; and power is shared<sup>1</sup> in ongoing, meaningful, constructive relationships at all system levels:

- Direct care
- Healthcare organization (service design, governance)
- Health system (setting priorities and policies)<sup>1</sup>

## 1.1 Why partner on patient safety and quality?

Canada's healthcare system is faced with growing healthcare costs, increasing rates of chronic disease, and an aging population. While it performs well on some measures, it ranks behind other Western countries on providing patient-centred care (eighth out of 11 countries), timeliness of care (11<sup>th</sup> out of 11), coordinated care (eighth out of 11), and safe care (10<sup>th</sup> out of 11). In 2014–2015, there was [at least one harmful incident for every 18 Canadian hospital stays](#) (138,000 out of 2.5 million hospital stays).<sup>3,4</sup>

Patients, providers, leaders, researchers, and policy makers now agree that patients and families are essential to ensuring safe and quality care. They are creating new knowledge and tools to accelerate patient engagement.<sup>5–12</sup>

Fundamentally, patients expect to be safe while receiving care. Evidence and practice increasingly show that patient engagement is important to prevent patient safety incidents from occurring, respond to incidents, learn from and improve care safety. Because [patient safety is an element of quality of care](#), engaging patients in patient safety is linked to other quality dimensions (e.g., accessible, appropriate, effective, efficient, equitable).

Here are a few reasons to engage patients and families:

### It's the right thing to do

Partnering with patients and families shows respect, values their insights and experience, and empowers them to take an active role in their care. Those working in the healthcare system are morally obligated to engage patients, whether as members of their care team and/or as partners in improving healthcare safety and quality within the healthcare organization or the whole system. “Nothing about me without me,” expresses this value.

### It's the safe thing to do

As respected partners, patients and families can improve their own care quality and safety. The 2014 Report of the Roundtable on Consumer Engagement in Patient Safety<sup>13</sup> described patients as being the extra sets of eyes and ears that should be integrated into the safety processes of all healthcare organizations because:

- They know their symptoms and their responses to treatments better than anyone else.
- They are highly invested in their own well-being and outcomes.
- They are always present in their own care, unless impaired by factors beyond their control. They are the first to know or feel when a symptom changes or they experience treatment impacts, and they can communicate these to their care team.
- Their courage and resilience can inspire and energize their care team.
- They often have insights into the processes of care that providers lack because the providers are focusing on getting the job done.

## It enables innovative solutions

Patient engagement has been called the “blockbuster drug of the century.”<sup>14</sup> Patients bring new, innovative approaches:<sup>6</sup>

- Patients offer a unique perspective to decisions about their own health and treatment, to co-o-design processes in their local health organization, or to the bigger policy decisions that shape the healthcare system. They are experts in their own care and are experienced health system users.<sup>5</sup>
- Engaged patients better understand and know more about their care, leading to better health service and resource use.<sup>15</sup>
- Partnering with patients in planning and designing healthcare services is an important way to improve care quality and accountability in the system.<sup>16</sup> Patient partners on incident review teams or committees:
  - Offer a unique perspective:
    - Another “discipline” around the table – specialized in the patient experience
    - An integrated view of systems, where providers only know about their own part of the care journey
    - New insights into incident analysis.
  - Involve those who are most impacted by decisions.
  - Allow providers to speak exclusively to their own role rather than trying to imagine the patient and family perspective.
  - Diversify team problem-solving and identification of solutions.

## It’s an expectation and a standard

Across Canada, governments and healthcare organizations are advancing patient and family-centred care, with patients and families taking on more active, informed, and influential roles.<sup>7,12</sup>

Healthcare organizations work with recognized accreditation bodies to review and strengthen their delivery of safe, high-quality care. The Health Standards Organization is developing standards that require patient engagement in governance, leadership, and service delivery. Evidence-based accreditation standards are evolving to require that organizations implement policies and practices to support patient engagement and shift to more people-centred care.<sup>17</sup> Since 2016, healthcare and social services organizations participating in Accreditation Canada’s Qmentum program are evaluated on people-centred care criteria to partner with patients and families in planning, assessing, and delivering their care and services. Since March 2018, clients can opt to include trained patient surveyors as part of their on-site accreditation process.

Moreover, the Health Standards Organization is now purposefully engaging patients, families, health service providers, clinicians and policy makers in the co-design and revision of health standards, ensuring that all points of view relating to a new standard or a proposed standard revision are represented.<sup>18</sup> The definition they are using for people-centred care is one from the World Health Organization<sup>19</sup>.

Some provinces have introduced legislation that requires organizations to engage patients in health system planning. For example, [Ontario’s Patients First Act](#) requires that patient and family advisory councils be put in place for every local health integration network.

Look for this icon to quickly identify alignment with Health Standards Organization



# 1.2 Current state of patient engagement across Canada

In Canada, patient engagement examples reveal courage, collaboration, innovation, and momentum for change in the face of significant obstacles. However, there is still a long journey ahead until patient engagement is standard practice in every interaction, every setting, and every sector. Since some of the major initiatives in Canada began around 2004, more evidence and changes that result in safer care at all system levels have been published.<sup>6</sup>

## Patients and patient groups become trusted partners

For many years, patient groups, often organized around a common disease or health condition, have actively advocated to partner in their own care, in decisions about setting health service and research priorities, and in care-design and delivery.<sup>20</sup> Since 2004, formal and informal patient groups have emerged and continue to emerge across Canada, indicating a strong desire to contribute to safe and quality care.

For more than a decade at the national level, patient groups like [Patients for Patient Safety Canada](#) and [Canadian Family Advisor Network](#) have worked collaboratively with many leaders, providers, and policy makers to include the patient’s perspective in service design and policy making. Their intent is to build a safer, more sustainable healthcare system that is responsive to patient needs. Patients shape tools, resources, guidelines, standards, and learning programs to help other patients, patient partners, providers, and leaders.

At provincial and local levels, patient groups like the [Patient Voices Network](#) in B.C., and [Health Quality Ontario Patient, Family and Public Advisors Council](#) shape provincial and local policies, frameworks, performance measures, and point-of-care interactions.

Informal patient groups and [networks](#) are also increasing in number. Patients are connecting, supporting each other, advocating for change, and collaborating with providers, administrators, [researchers](#) and policymakers to make positive changes in the healthcare system. Learn about Canadian and provincial patient organizations and other organizations supporting patient engagement [here](#).



Emerging efforts focus on building connections among different patient groups in a “network of networks,” primarily by Patients for Patient Safety Canada (PPSC), the patient-led program of the Canadian Patient Safety Institute and the Canadian arm of the World Health Organization’s Patients for Patient Safety Global Network. Patients for Patient Safety Canada has facilitated the creation of the [Patient Alliance for Patient Safety](#), whose purpose is to improve the safety of care through collaboration. The common patient safety issue the Alliance will address is improving the safety of care journeys through public engagement. Through meetings and building relationships, the Canadian Patient Safety Institute helps reduce duplication, transfer knowledge, and align efforts to achieve a common goal: safer care through patient engagement.

## Grassroots efforts became embedded at all system levels

Early efforts in patient engagement for patient safety and quality grew out of the grassroots work of patients, clinicians, and leading healthcare organizations in patient and family-centred care.<sup>21–26</sup>



- The [Canadian Foundation for Healthcare Improvement](#) (CFHI) supports organizations to purposefully engage patients and families in quality improvement initiatives. This program helped seed a nationwide patient and provider learning community to build evidence for the positive impact of engaging patients.<sup>5</sup>
- The Canadian Patient Safety Institute’s [National Patient Safety Consortium](#) identified patient engagement as a key focus area in the collective effort of key patient safety and quality organizations. The Canadian Patient Safety Institute has been modelling patient engagement in patient safety for more than a decade by ensuring that 100 per cent of programs are developed and delivered in partnership with patients. The Canadian Patient Safety Institute also develops specific [resources for patients and the public](#), and supports [Patients for Patient Safety Canada](#).
- HealthCareCAN helps train healthcare professionals and organizations through a comprehensive and practical online learning program focused on [People-Centred Care Leadership](#).
- Health Standards Organization introduced people-centred care standards to support organizations increase patient engagement and to advance quality and safety in healthcare organizations across the country.
- The [Canadian Institute of Health Research](#) is advancing its own organizational strategy for citizen engagement. Patient engagement is a pillar of its [Strategy for Patient-Oriented Research](#), with provincial and national capacity-building initiatives underway.

At the provincial and territorial levels, jurisdictions have launched structures and strategies to progress safe and quality care through patient engagement and people-centred care:

- Cancer Care Ontario launched a revised model for engagement in September 2019, co-designed with patient partners. The model highlights how the culture of engagement can be improved through human centered design, community building, digital supports, training and support, fostering human connections and active listening.<sup>27</sup>
- [Saskatchewan’s 2009 Patient First review](#) included patient and caregiver opinions in setting priorities for provincial health system reform.<sup>28</sup> These priorities continue to shape progressive change that embeds “Patient First” as a core value and focuses on improving the patient experience. The [Saskatchewan Health Quality Council’s](#) number one priority is to integrate patients and families as partners in all aspects of healthcare.<sup>29</sup>
- [British Columbia’s Patient Voices Network](#) is administered by the BC Patient Safety & Quality Council (BCPSQC) and recruits, trains, and supports patients to partner in change processes that improve care and service design. Health authorities and other stakeholders collaborate to identify opportunities for engagement. In partnership with [BCPSQC](#), Patient Voices Network has developed a [guide](#) covering the essence of patient engagement.
- [Health Quality Ontario’s Patient Engagement Framework](#) guides a provincial strategy to build capacity for patient engagement across the provincial health system and in its own organization.

- The Minister’s Patient and Family Advisory Council released the [Patient Declaration of Values of Ontario](#) to provide guidelines for developing programs and services that support patients as being partners in their care across the healthcare system.
- Vancouver Coastal Health has a Community Engagement Advisory Network ([CEAN](#)), which is a group of members of the public that support patient and public involvement in health services planning and decision making.
- [Manitoba Institute for Patient Safety \(MIPS\)](#) is the first provincial organization to engage the public in self-advocacy for safe care,

The Health Quality Council of Alberta (HQCA) Patient and Family Advisory Committee started as a strategic initiative through the provincial [Patient Safety Framework](#) for Albertans and works to leverage the experiences and perspectives of patients and their families to improve and promote patient safety and health service quality in Alberta’s healthcare system. This group is structured as a committee of the HQCA’s Board of Directors to ensure a direct line of connection between the patient/family perspective and the Board.

Many more health authorities and healthcare organizations are taking steps to integrate patient engagement into their work:

- Kingston General Hospital in Ontario introduced the first organization-wide patient engagement policy. Patient partners are now on all major committees and are involved with hiring decisions, staff orientation, and healthcare provider education.<sup>6</sup>
- Capital Health Authority in Nova Scotia (now the [Nova Scotia Health Authority](#)) introduced a policy<sup>30</sup> that embraces patient and citizen engagement as a core value and business process, offering tools and consultation support to build engagement capacity.
- The Centre intégré universitaire de santé et de services sociaux de la Mauricie-et-du-Centre-du-Québec, has developed an [integrated strategy based on three principles](#): (1) shared leadership between a patient and a manager to build the strategy; (2) a clear process for recruiting, training, and coaching patient advisors (PA) so that they can participate in decision-making at the various levels of governance of the establishment; and (3) a feedback process for improving the strategy over time.<sup>31</sup>

Visit our [website](#) for more examples of leading practices.

## Gaps in current practice

While there has been significant progress, many organizations who have achieved safer care through patient engagement, more needs to be done.<sup>32</sup> Several recent reports point to the need to engage patients and the public, integrate care services, ensure the safety of healthcare workers, and increase equity and transparency across the continuum of care.<sup>33,34</sup>

A [national consultation](#) commissioned by Health Canada in 2015 found that more needs to be done to increase patient engagement in organizations and the healthcare system.<sup>6</sup> The report found that providers and administrators in Canada’s healthcare system acknowledge that patients – and their perspectives and experiences – should be the guiding factor in clinical care. However, the degree of patient engagement in care varies. Also, while most healthcare organizations collect patient feedback using surveys and most providers share information with patients about their diagnosis and journey of care, many patients said they expect better communication to help them manage their own health, and greater involvement and more collaborative, integrated care that respects their needs.

*The Case for Investing in Patient Safety 2017 report* found the following results:<sup>35</sup>

- Every 1 minute and 18 seconds, a Canadian experiences a preventable patient safety incident
- Preventable patient safety incidents are the 3<sup>rd</sup> leading cause of death in Canada, behind cancer and heart disease
- Over the next 30 years, in acute and homecare settings, there could be roughly 400,000 preventable incidents/year costing around \$6,800/patient and generating an additional \$2.75 billion (2017) in treatment costs/year
- The biggest driver for incidents in acute care settings will be infections and in homecare setting traumas (e.g. falls)

The *Patient Safety in Canada 2018 report*<sup>36</sup> shows that one in three Canadians have experienced a patient safety incident (e.g. misdiagnosis, falls, infections) and that Canadians are concerned about incidents and want to know how to keep safe.

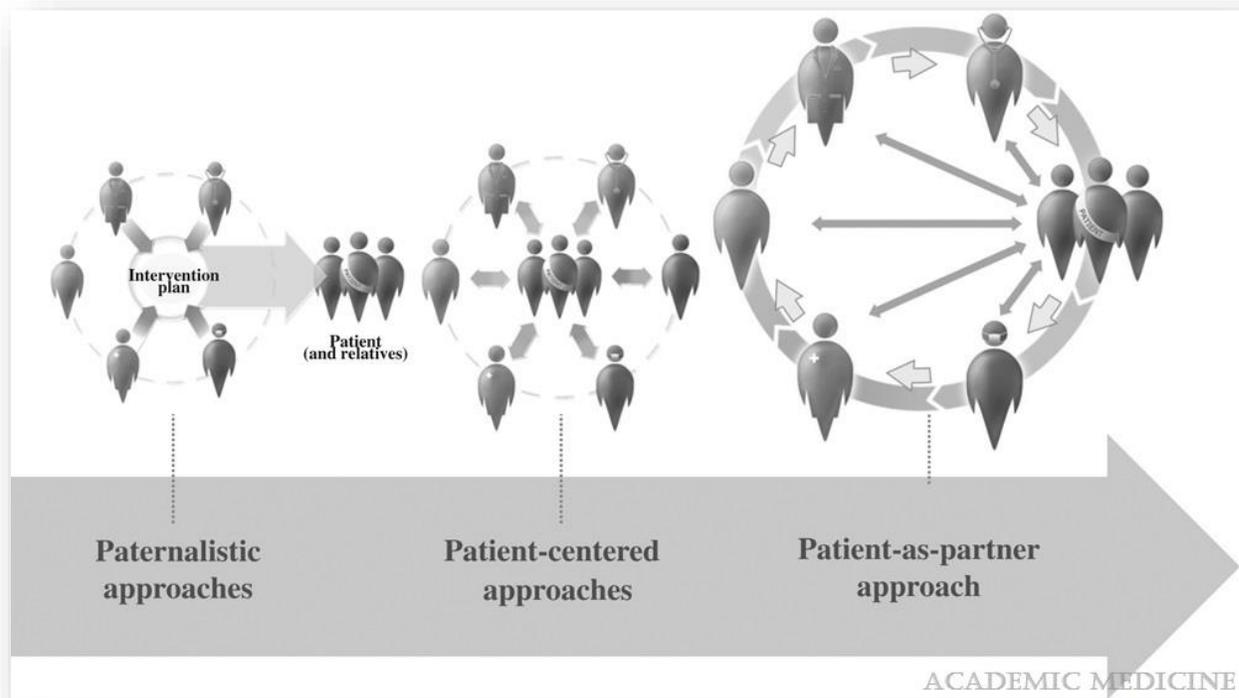
In 2019, the World Health Organization passed the *Global Action on Patient Safety resolution* that highlights the global burden of patient harm due to adverse events (estimated as one of the top 10 causes of death and disability in the world) and the new impetus for global action. It argues that patients, families and communities as the co-producers of health are key to the provision of safe care: “safe care and protection from harm should be the right of every individual treated in a health care system”.<sup>34</sup> As a WHO [Collaborating Centre in Patient Safety and Patient Engagement](#), the Canadian Patient Safety Institute has and will continue to lead the way so Canada has the safest healthcare in the world.

While partnering with patients is a recognized strategy to improve safety and quality of care, more work needs to be done to:

- Create a culture that supports partnership and collaboration
- Provide supporting structures and policies, information, and tools
- Ensure the purpose of the patient participation fits the needs, preferences, and capacity of those engaged

To close the gap in practice, a good starting point is to understand the patient engagement approach currently used. According to the [Direction of Collaboration and Patient Partnership](#), University of Montreal, in paternalistic approaches the work of healthcare professionals is centered on the intervention plan, and patients take little part. Patient-centred approaches put patients at the center of the healthcare professionals’ work and concerns. In the patient-as-partner approach, patients are members of the health care team; like all other team members, they bring their unique expertise.

## Three approaches for patient engagement



© Direction of Collaboration and Patient Partnership, University of Montreal, 2013 (reproduced with permission).  
Source: [The Patient-as-Partner Approach in Health Care: A Conceptual Framework for a Necessary Transition](#).  
Academic Medicine:90(4):437-441, April 2015.

# 1.3 Evidence of patient engagement benefits and impact

Because patient engagement in healthcare is still a relatively new approach, few high-quality studies have been conducted to demonstrate its impact.<sup>5(pp11-34),26,37</sup> There is emerging evidence that shows real-world improvements in health outcomes and healthcare delivery from partnering with patients. Most evidence is from pilot projects, formal case studies, and anecdotal evidence from patients and providers. [Imagine Citizens Collaborating for Health \(Alberta\)](#)<sup>38</sup> considers a broad definition of evidence that includes five sources. Understanding healthcare challenges and identifying solutions requires looking at research alongside other evidence.

The research in patient engagement is still catching up with current practice, including the most innovative approaches.<sup>26,39</sup> Even without research evidence, a growing number of Canadians expect that healthcare decision-making reflects patient priorities and is based on collaborative partnership at all levels.<sup>9,40</sup>

It simply makes good sense to partner with patients to better understand their experience and needs. This deeper understanding informs those who design and provide care to focus efforts on improving patients' well-being and quality of life.



## How partnering with patients is making an impact

Examples of how [patient engagement makes a difference](#) in safety and other quality areas are included in the following table.<sup>41,42</sup> Some outcomes (e.g., efficiency) are linked to other quality areas and are described as “integrated” indicators in the Health Quality Ontario’s Indicator Technical Specifications – Quality Improvement Plans 2015/16.

Select quality areas	Example of improvements
Safety	<ul style="list-style-type: none"> <li>Improved hand hygiene rates and reduced infection rates</li> <li>Better medication self-management<sup>43</sup></li> <li>Reduced patient safety incidents, such as medication errors or patient falls</li> <li>Increased identification of potential safety issues by patients and families that prevent safety events from occurring<sup>44,45</sup></li> </ul>
People-centred care	<ul style="list-style-type: none"> <li>Reduced anxiety and stress with the presence of family/supports</li> <li>Improved patient/provider communication</li> <li>Better understanding of health, options, and the care plan</li> <li>Improved patient satisfaction and care experience<sup>46</sup></li> </ul>
Coordination of care	<ul style="list-style-type: none"> <li>Better transition from hospital to home, discharge planning</li> <li>Improved interprofessional teamwork</li> </ul>
Equity	<ul style="list-style-type: none"> <li>Improved cultural awareness and consideration when providing services</li> </ul>
Health outcomes <sup>47</sup>	<ul style="list-style-type: none"> <li>Improved patient emotional health</li> <li>Better symptom resolution, functioning, pain control</li> </ul>

Select quality areas	Example of improvements
	<ul style="list-style-type: none"> <li>Improved physiologic measures, (e.g., blood pressure, blood sugar levels)</li> <li>Decreased death rate for people with chronic obstructive pulmonary disorder<sup>5</sup></li> </ul>
Effectiveness and appropriateness	<ul style="list-style-type: none"> <li>Improved care and service delivery after co-design with patients, (e.g., staff wearing identification badges, purposeful hourly rounding at the bedside)</li> <li>Reduced rates of preventable readmissions to hospital<sup>48</sup></li> <li>Reduced lengths of stay in hospital<sup>46</sup></li> </ul>
Efficiency	<ul style="list-style-type: none"> <li>Lower costs per patient stay in hospital</li> <li>Better staff recruitment and retention and staffing mix</li> <li>Lower medical and legal costs from lawsuits against the provider/organization</li> </ul>

### Impact on patient safety

Studies show that patients and families can provide unique safety information and be valuable partners in safety surveillance.<sup>44,45,49,50</sup> For example:

- In 2008, a study of 998 recently hospitalized patients in Massachusetts found that patients identified about twice as many of the harmful patient safety incidents that took place during their hospital visit as the providers who reviewed the medical records.
- A recent study of more than 746 parents/caregivers of hospitalized children found that they reported similar rates of errors and harmful patient safety incidents as providers. They also reported five times more errors and three times more harmful incidents than those recorded in formal hospital incident reports. Overall detection rates of errors increased by 16 per cent, and harmful patient safety incidents increased by 10 per cent.

Evidence proves that involving patients can help improve infection control (e.g., their own hand hygiene, the hand hygiene of their providers).<sup>51</sup> The [Women’s College Hospital](#) successfully engages patients as observers in hand hygiene.

A 2018 report “[Strategically Advancing Patient and Family Advisory Councils in New York State Hospitals](#),” found that hospitals with patient and family advisory councils (PFACs), had a significantly higher Hospital Consumer Assessment of Healthcare Providers and Systems scores, which support the notion that PFACs are an important way to engage patients and their families for better healthcare outcomes.<sup>52</sup>

Other academic articles are cautious about stating the positive impacts of engaging patients in patient safety.<sup>37,43</sup> For example, not all patients are interested in being actively involved in identifying patient safety incidents. In some cases, patients and providers do not agree on what should be considered a patient safety incident. Data on patient experience does not include enough patients over a long enough period to provide good quality, generalizable results.

### Impact on staff

There is some evidence that patient engagement can increase healthcare provider satisfaction and engagement, improving recruitment and reducing staff turnover, sick time, and overtime.<sup>41</sup> This contributes significantly to delivering safe and quality care.

## Impact on patient partners

In many cases, a personal experience with harm motivates patients to get involved and volunteer for safer care. Sharing personal stories and partnering for change can be part of the healing process<sup>53</sup>. This intimate experience allows patients to contribute valuable insights into preventing and responding to harm.

## Evidence on promising practices for engaging patients in direct care

The Partnerships for Patients initiative found that the more that patients were engaged in their care, the greater the potential to prevent their readmission to hospital.<sup>54</sup> The hospitals that had achieved four or five metrics were more successful in keeping patients out of hospital following discharge.

A 2017 evidence review analyzed the impacts of practices that engage patients in direct care.<sup>26</sup> The following practices can lead to better outcomes in safety, quality, and patient experience:

- Shared decision making with patients
- Family presence and involvement in care
- Advanced care planning
- Compassionate care delivery
- Provider training to improve their ability to partner and to improve empathy and communication skills

A 2012 academic journal article presents the evaluation results from research studies (e.g., trials, systematic reviews) on patient engagement approaches, including the evidence that support the most promising approaches.<sup>55</sup>

## Evidence on engaging patients in health research

Some evidence shows that patient involvement in health research can result in research that is more focused on patient needs and help bring the research results into practice. For instance, patient engagement can lead to improvements in Emergency Medicine research by allowing researchers to select meaningful outcomes, improve and increase social acceptability studies, and arrange knowledge translation strategies that focus on patients' needs.<sup>56</sup> Additionally, Patient-Centred Outcomes Research Institute has developed an [evaluation framework](#) that assesses the short- and long-term impacts of patient engagement in a research setting.<sup>57</sup>

Evaluating patient engagement in research is still in its early stages and the best methods of engagement are not yet well understood.<sup>58</sup> For more examples on evidence of engaging patients in health research, check [CIHR SPOR](#).

## Building stronger evidence for patient engagement

To build a stronger evidence base, systematic patient engagement monitoring and evaluation is crucial. Equally crucial is sharing and spreading existing learning, knowledge, research, and practices. A stronger evidence base will help build better and more relevant programs, policies, and strategies to help accelerate patient safety and quality efforts.

## 1.4 Challenges and enablers to patient engagement

“Patients and families face challenges, the most critical being the need to convince more healthcare organizations and service providers to engage patients and families in every aspect of patient safety initiatives. These include health professional education, meetings, consultations, advisory committees, patient safety councils, research and knowledge transfer initiatives, disclosure guidelines and policies and patient safety policies. What is currently in place in these areas is not working, and transformation requires everyone’s commitment.”<sup>59</sup>

### Patient engagement challenges

Some common challenges related to patient engagement in general are also common to patient engagement in patient safety.<sup>20,41,60</sup> They range from shifting the culture towards engaging patients as partners, to the operational aspects of practicing engagement.

#### Shifting culture

Changing from a provider-centred mindset and care system involves rethinking the current policies, structures, and processes that get in the way of patient engagement. It means shifting the culture from individual services delivered by professionals or experts to integrated, collaborative care.

Healthcare providers and leaders may be concerned that:

- Patient perspectives might differ from their own and lead to unwanted change
- Patients might not have the required knowledge to participate meaningfully
- Patients may not be clear on the advisor role
- Patient readiness to partner collaboratively or constructively may be affected if they have had a negative experience of care
- Patients might lose confidence in the healthcare organization (e.g., while learning about and discussing challenges with care processes, safety risks, or patient safety incidents that have resulted in harm)
- Patients may not respect privacy and information confidentiality
- Decision-making authority and roles could lead to confusion and unmet expectations.

The governing body provides oversight of the organization's efforts to build meaningful partnerships with clients and families.

Governance 5.3



Patients may also have fears or demonstrate resistance because:

- Providers are the experts and patients should defer to their advice and direction
- Responsibility and accountability will be shifted onto the patient
- Patients might not have the confidence, knowledge, and ability to be partners
- Patient engagement will be token and their input will not be used to make decisions
- Speaking out may lead to reprisals, further preventing patients from reporting safety incidents<sup>61</sup>

## Practicing engagement

Making patient engagement a priority in practice and in the hearts and minds of patients, providers, and health leaders is challenging for many reasons, including:

- Competing priorities
- High demands on providers at the point of care
- Limited healthcare resources
- Pressures to increase efficiency
- Inadequate healthcare provider time, resources, and expertise to support patient engagement
- Lack of diversity in the patients engaged (i.e., not representative of the populations served)
- Patients and providers may lack knowledge, skills, and experience in patient engagement
- Scheduling meetings and working within the limits of a patient's volunteer time
- Adapting to changes in a patient's health status when dealing with chronic conditions
- Identifying opportunities for meaningful patient engagement
- Sustaining patient and provider interest in the work over time
- Bureaucracy and technicalities (e.g., sharing information that is protected by privacy regulations)
- Some staff report not feeling confident or prepared enough to engage patients as partners
- Culture change/shift takes time, which can be challenged by a focus on reactive versus proactive practices and responses
- Size of an organization is also a considerable challenge in communicating and supporting change

An important factor supporting meaningful engagement is the feedback loop. Patient partners need to know how their engagement made a difference, how their feedback was used to support change. Considering a practice for ensuring feedback loops are embedded in the engagement process is crucial at the outset of any engagement activity.

Key challenges and future opportunities for patient involvement in patient safety: <sup>62</sup>

- Engage more meaningfully with vulnerable patients on their turf and their terms
- Engage in design, measurement, and improvement of services
- Embrace a more expansive view of safety and risk (including presence of safety & past harm)
- Consider the entire pathway, not only organizational and professional boundaries
- There is no one right type of engagement
- Following-through and closing the loop after an engagement to ensure learning and improvement

## The unique nature of patient engagement in patient safety

There are specific challenges to engaging patients in their safety at the point of care, organization and system levels.<sup>63</sup> When patients are asked to help identify potential safety risks, they may be reluctant to discuss their safety concerns with providers due to:

- Fear that speaking up could impact relationships and future care
- A belief that they may not be qualified enough to contribute (e.g. can't speak on behalf of all patients, just personal experience)
- Concern that engaging in patient safety will trigger reactions that may harm them again or harm others

Providers may also resist engaging their patients in safety matters due to:<sup>42</sup>

- The amount of effort, time, and resources required to engage in the patient safety activity
- Fear of repercussions if they share incidents with patients, team members, and the organization
- Fear of re-traumatization in the case of providers who were involved in a patient safety incident

As well, organizational patient safety performance targets and incentives may not always be consistent with patient engagement.

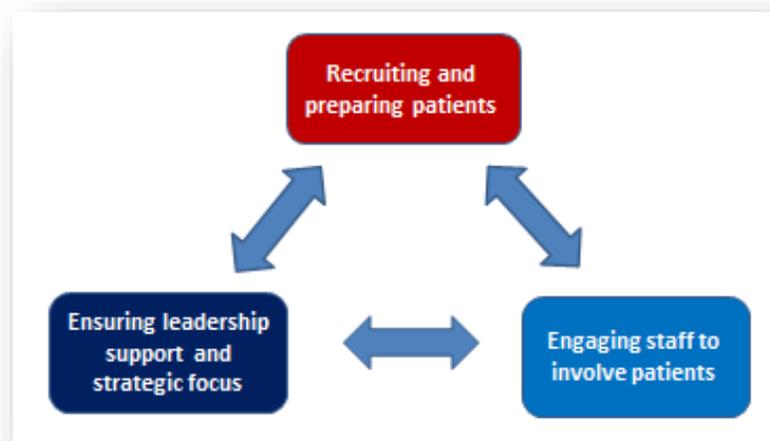
According to Patients for Patient Safety Canada, the patients and family members who experienced unsafe care (an incident or near miss) are best suited to engage in patient safety efforts. Patients for Patient Safety Canada has been using this approach since their inception in 2006 (in line with the WHO Patients for Patient Safety Programme requirements) and over time developed an effective approach for membership recruitment, orientation and engagement<sup>64</sup>. Learn more [here](#).



## Patient engagement enablers

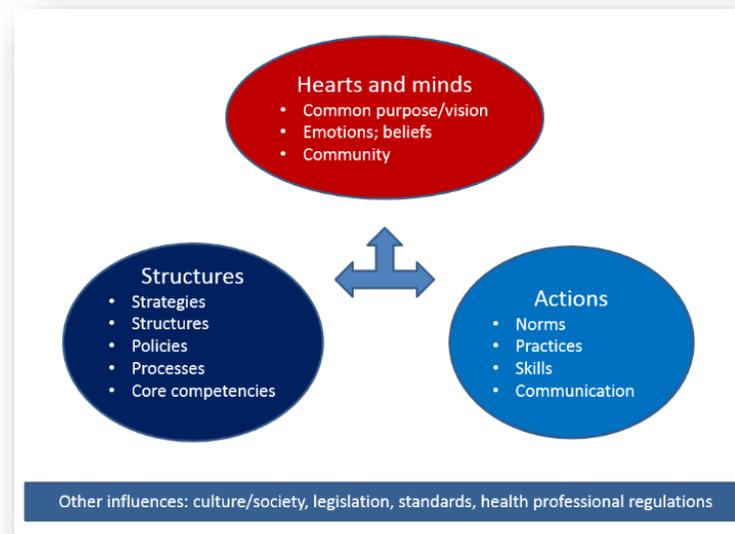
Based on a research and practice review, researchers found three tightly linked factors that reinforce each other to enable patient engagement:<sup>5</sup>

1. Recruiting and preparing patients as partners and team members and in other roles.
2. Engaging healthcare providers to involve patients as partners in teams, councils, boards, and other bodies.
3. Ensuring leaders support patient engagement and patient and family-centred care across the organization and at the point of direct care.



A way to support patients, providers, and leaders to influence patient engagement includes focusing on:<sup>65</sup>

1. Shifting hearts and minds through a common purpose and vision. Partnership and collaboration are the organizational culture and patient engagement is a visible and lived value tied to a commitment to people-centred care.<sup>41</sup> People need to think, feel, and believe it.
2. Supporting action through norms, practices, and communication. Reinforce partnership, engagement, and opportunities to build skills in patients and providers.
3. Putting supportive structures in place (e.g., policies, processes, and expected core competencies). Embed patient engagement throughout the organization and at the point of care.



There are specific, interconnected factors that enable patient engagement in patient safety, influenced by a culture of safety. To enable patient engagement, organizations should:<sup>66</sup>

- Collect, analyze, and actively share relevant safety information
- Create an atmosphere where people are confident and feel safe to report safety concerns without fear of blame. They need to trust that concerns will be acted upon.
- Consider preventable patient safety incidents as opportunities for learning and make changes as a result
- Balance policies and practices to address system failures and clarify responsibilities
- Believe people can adapt effectively to changing expectations

## Culture and leadership as patient engagement critical enablers

“A culture that is caring and supports partnerships, continuous system improvements, teamwork and accountability will naturally lead to an unrelenting desire to pursue the perspectives of patients and families in everything the organization does.”<sup>41</sup>

### Culture and values

Culture is commonly described as “the way we do things around here,” and is rooted in people’s attitudes, beliefs, and actions. Organizations that have been successfully engaging patients for a long time have cultures that engage patients in all major activities and decisions. They also place patient engagement front and center when designing and delivering safe care.

Preventing and responding to patient safety incidents requires systemic actions to improve the many connected factors that impact a safety culture.<sup>67,68</sup> Organizations should combine improvement efforts in safety and quality with patient engagement to include every aspect of care and every strategy.<sup>5,69</sup>

A safety culture applies to everyone involved in care processes and systems, including patients, providers, and leaders (i.e., everyone has a role and a responsibility). To be successful in nurturing this culture, organizations should strive towards:<sup>66</sup>

- Leadership and board commitment, and visibility
- Effective and open teamwork and communication at all levels
- Team members, including patients and families who openly report problems and incidents, and measure, monitor, and learn from safety incidents
- Organizational learning
- Organizational resources for patient safety
- Values that prioritize safety over production (e.g., efficiency, cost)
- Education, training, and resources so everyone knows how culture supports patient safety and their role within it

Making a cultural change requires:<sup>70,71</sup>

- A long time-frame to make the change
- Setting clear, realistic goals, and measuring progress
- Supporting partnership and collaboration
- Helping people understand the purpose and the benefits of engagement
- Linking patient, family, and provider experiences
- Encouraging learning by doing and learning together

Amy Edmondson’s, 2018 book *The Fearless Organization*, references many examples where psychological safety is linked to patient safety.<sup>72</sup> Psychological safety means that people believe they can, and must be forthcoming. It is expressed through candor, transparency and learning from error. It is founded on principles of honesty, vulnerability, communication, and information sharing. Creating a psychologically safe workplace is an ongoing function of leaders who need to: set the stage, invite participation, and responding productively.

## Leadership and governance

Leaders are critical to patient engagement. Leading healthcare organizations prove that senior leaders can lead by example and shift culture and practice by setting the tone, creating a supportive environment, and providing resources to engage patients and families. A strong mission, vision, values, and strategy will not move to action without visible and practical leadership commitment. This commitment needs to be embedded in orientation of new staff at the outset, and in ongoing education for all.

Teams are supported in their efforts to partner with clients and families in all aspects of their care.

Leadership 1.4



Effective patient engagement and people-centred care leaders:<sup>5,73</sup>

- Are visible champions (e.g., share patients' care experiences; report on patient partnerships and engagement impacts to the board, staff, and patients; and communicate the organization's commitment to patient engagement)
- Link patient engagement efforts to other organizational strategies (e.g., improve care processes and outcomes, advance safety, and quality)
- Engage patients and staff in developing shared engagement goals to improve safety<sup>69</sup>
- Are role models for partnering with patients and family members (e.g., seek out and act on patient advice, invite patients to participate at meetings, work with patient partners to identify priorities and develop strategies)
- Provide the necessary infrastructure, people resources, and budget for patient engagement.
- Ensure systems are in place to:
  - Bring the patient experience into organizational planning, priority-setting, and improvement initiatives
  - Support patients to identify and report safety risks, and report complaints and patient safety incidents
  - Monitor and evaluate the results of engagement, including partnerships and collaboration.
  - Cultivate a learning environment that connects patients with providers for collaborative learning
- Involve and support clinicians and hospital staff in patient engagement initiatives
- Integrate patient engagement into human resource policies and practices

For patient and family-centred care strategies to be properly developed and implemented, healthcare organizations should strive towards:<sup>41</sup>

- A vision, mission, values, and principles that collectively point to the reasons why patient engagement is necessary
- Ensuring that everyone understands the concept, including the organization's board, senior leaders, providers, patients, and families
- Clearly explaining and showing that patient engagement is critical to achieving patient and family-centred care in care processes, decision making, and service design

Many provinces and leading healthcare organizations have developed a vision, mission, values, and principles to advance patient and family-centred care and patient engagement. For example, Alberta Health Services (AHS)<sup>74</sup> values tie compassion and respect together with patient safety, accountability, and excellence; the [Patients First](#) strategy and the [Patient Safety Framework for Albertans](#) puts patient engagement front and center for patient safety.

# 1.5 Embedding and sustaining patient engagement

Aligning and embedding patient engagement in structures, policies, and processes helps achieve and sustain patient safety outcomes. At the point of care, patient engagement can help patients and providers interact more effectively. Examples include policies for family presence, [bedside shift reports](#), [discharge planning and care transitions](#).

At organization and system levels, patient engagement is stronger and more sustainable when it is in formal structures so patient partners can shape broader strategies. Their perspective is even more valuable when it impacts multiple organizations to enhance care transitions and coordination. Ideas include:

- Engaging patients in [governance and decision-making](#) (e.g., patient partners on boards, steering committees, and quality and safety committees, patient and family advisory councils or patient groups)<sup>31</sup>
- Engaging patients in co-designing formal processes to collect and include patient experience in decisions (e.g., reporting and learning structures that include patient feedback, compliments, and complaints, and reported incidents)<sup>75</sup>
- Preparing people when they are healthy to understand the important role they play in achieving safe care-outcomes by learning, asking questions, and advocating for self and others

**Patient partner (advisor) involvement process<sup>31</sup>**



Four themes identified for embedding patient engagement:<sup>76</sup>

- Wanting control
- Feeling connected
- Encountering roadblocks
- Sharing responsibility for safety

Patient comfort level and control over their own health were found to be important factors for patient engagement in patient safety practice. Ensuring that patients and providers have the necessary time to interact with one another, and in an open environment, is an essential component in promoting greater patient engagement in both their healthcare and patient safety.

Patient engagement infrastructure and resources include:<sup>73</sup>

## Organizational structures

To be effective, organizations should have formal structures that are accountable for patient engagement, such as:

- A dedicated office/department (e.g., patient experience)
- Within the quality and safety function/department, or
- Within the communications and public relations function/department
- A steering committee

When no formal organizational structure exists, organizations can build relationships with and gain support from external patient groups, like [Patients for Patient Safety Canada](#), provincial quality councils or health authorities. The [Health Quality Council of Alberta](#), for instance, is a provincial agency that pursues opportunities to improve patient safety and health service quality for Albertans.

## Staff position(s)

Many organizations have added one or more patient engagement specialist roles, commonly responsible for:<sup>77</sup>

- Recruiting, selecting, training, and supporting patient partners
- Setting up and supporting patient and family advisory councils
- Planning and implement engagement activities
- Developing and delivering training to patients and providers
- Monitoring and reporting on patient engagement
- Evaluating patient engagement initiatives and strategies

If there is no dedicated role to support patient engagement, staff with these responsibilities should be allocated dedicated time to carry out the work.<sup>78</sup> Patient partners often work alongside formal staff to co-lead patient engagement (e.g., as co-chairs).

## Financial resources

Budgets and financial policies need to include patient engagement and compensation for patient partners. See the Change Foundation's *Should Money Come into It? A Tool for Deciding Whether to Pay Patient-Engagement Participants* and Saskatchewan Health's policy on Patient and Family Advisor Program Compensation and Reimbursement. Financial resources are crucial to support engagement. For instance, access to support for travel, especially to participate in person at least for the initial meeting and following a couple of times a year is crucial to supporting patient partners feeling they are meaningfully engaged. This supports a better connection to people and the role and sustainable commitment, which is a necessary component when geography is a challenge.

Patient safety and patient engagement in care is supported by patient access to their health information which requires longer-term plans for investment in digital health.<sup>6,73</sup>

## Human resources

Human resource departments can promote patient engagement through recruitment, orientation and support to providers, leaders and staff by ensuring:<sup>73,79,80</sup>

- Job descriptions include basic patient engagement principles
- Interview questions include patient engagement
- Interview processes and panels include patient partners
- Orientation includes patient engagement, patient experiences, and patient partners
- Performance appraisals encourage continued skill development
- Professional development opportunities on patient engagement are offered

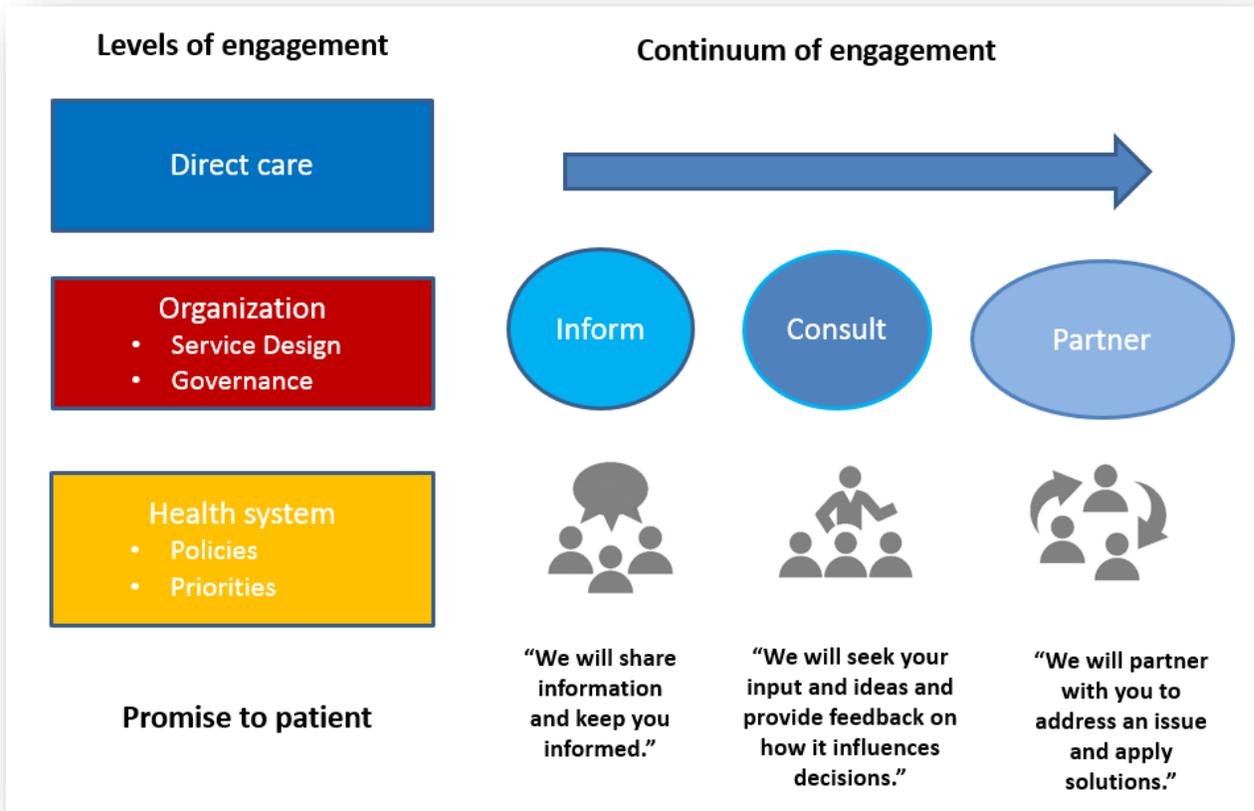
There are training programs that can help increase the staff's competencies towards engagement. An example is the online People-Centred Care Leadership Certificate program<sup>41</sup>, developed by HealthCareCAN in partnership with the HSO, designed to enable healthcare professionals at all levels to lead healthcare change and improvement in partnership with patients, families, and providers. Explore what is available in your own organization or network.

# 1.6 Patient engagement continuum

The engagement continuum ranges from low-level, where information is shared by providers with patients, to high-level partnership, collaboration, and shared decision-making. All engagement levels are appropriate depending on the purpose of engagement. Patients, families, and patient partners should be determining together with care providers and leaders what the most appropriate level of engagement is for each situation.

Two patient engagement frameworks commonly used in the healthcare system in Canada are the [Carman Framework](#), developed by the American Institutes for Research, and the International Association of Public Participation’s [Spectrum of Public Participation](#). Some Canadian provinces are using these frameworks or have developed their own, such as the [Health Quality Ontario’s Patient Engagement Framework](#). This graphic, with permission from Health Quality Ontario, was adapted from these three frameworks.

**Patient engagement continuum**



## 1.7 Summary - What you can do



### Patients, families, and patient partners

- Learn about and use resources to help you have a safe care experience
- Share your expectations and needs
- Discuss your ideas for improving safety and listen to different perspectives
- Ask about patient feedback surveys or formal compliments and complaints process
- Learn:
  - Who is responsible for patient engagement
  - How the patient experience is included in services and care-design planning
  - How to connect with other patients and families
- Find out how to participate as a patient partner to make care safer for others:
  - Join a board or committee
  - Get involved in an improvement project or initiative
  - Help with the accreditation process



### Providers, patient engagement specialists

- Learn about and use resources to engage patients for safe and quality care
- Understand and apply leading patient engagement practices
- Are able to answer common clinical questions related to patient safety
- Create an open, safe, and collaborative environment to share ideas or diverse perspectives.
- Set expectations for working together (e.g., roles, responsibilities, realistic goals)
- Know:
  - Who is responsible for patient engagement in your healthcare organization
  - How your healthcare organization brings the patient experience into services and care-design planning
  - How to connect with patient partners in the organization
- Look for or create opportunities for patient engagement in safety and quality improvement:
  - Ask patients and families about their care experience and seek out improvement ideas
  - Invite input on service planning or improvement projects. Test new ideas and monitor progress. Follow up on how the input was used and the project's results.
  - Ensure feedback loops are embedded in all engagement activities.
  - Collaborate with patients and families on long-term improvement projects. Build in time to reflect on what is working well and what could be improved.



### Leaders

- Foster a culture of patient safety and psychological safety through patient engagement
- Commit to patient and family-centred care and patient engagement by embedding it in the organization's vision, mission, principles, and strategies
- Incorporate multiple strategies to help providers pursue answers to their safety questions
- Clearly link patient engagement with organizational strategies and patient safety
- Walk the talk:
  - Champion new policies and processes that strengthen patient engagement
  - Promote and support opportunities for patient partners to be meaningfully engaged
  - Work towards patient engagement at all decision-making levels (e.g., boards, quality and safety committees, improvement teams, accreditation)
  - Allocate resources and funding for engagement and patient partner activities
- Ensure sustainable structures and processes for patient engagement (recruit, orient, train)
- Create a mutual learning environment for patient and family partners, staff, and physicians
- Provide opportunities for learning, testing, and adapting patient engagement best practices

## 1.8 Practice example

### Patient engagement on committees and initiatives - McGill University Health Centre

McGill University Health Centre's longstanding history of including patient representatives on organization-wide committees and the board of directors is summarized in [Creating Engagement Capable Environments in Healthcare](#).<sup>42</sup> Since 2010, patient representatives participate on quality improvement teams with staff. Involving patients on quality improvement teams started with a pilot project on five units, where work was underway to strengthen patient care at the bedside.

This co-design approach spread to 19 units, with many newly developed or redesigned processes and materials (e.g., use of whiteboards to improve communication, better nursing hand-offs at shift change). Results from the pilot project with the first five units include:

- 60 per cent decrease in medication incidents.
- Eight per cent increase in registered nurses' direct time in care.
- Increased patient satisfaction.
- Cost savings in equipment.
- Decreased infection rates (25 per cent for clostridium difficile and 26 per cent for vancomycin-resistant enterococci).
- Improved team effectiveness.
- Statistically significant reduction in nurses' voluntary turnover and overtime.



**Partners at the point of care**

## 2. Partners at the point of care

The patient perspective obtained during consultations for the development of the Canadian Disclosure Guidelines, states: “When things go wrong, patients and families need to know what happened. We need to hear the words “I’m sorry” from those involved in the event and, where appropriate, we need to see and hear the organization accept responsibility for their part in the event. When patients and families sense that information is being withheld, we lose trust and we are more anxious, fearful, and angry. We do not expect perfection, but we expect honesty, justice, and shared learning. Disclosing a patient safety incident with honesty, openness, and compassion shows respect for the patient and family. It shows that the organization is worthy of our trust and that the needs of the patient and family are paramount.”<sup>81</sup>

Patient safety requires that patients and families (or their advocate) partner with providers to prevent patient safety incidents. When these incidents do happen, patients, families, and providers can take actions to protect those involved from further harm, allow them to heal and understand what happened, and to make improvements to the process or system. Rather than blaming or punishing, the goal is to balance and understand care processes and systems that may cause patient safety incidents. How patients, families, and healthcare providers interact at the point of care is central. Everyone involved has a significant opportunity to take individual actions and collaborate to enhance patient safety.

Patient and family experiences and perspectives can help prevent harm and incorporate safety considerations proactively in system design at the point of care. At the core, this chapter answers these questions:

- How can patients and families engage with providers at the point of care to prevent patient safety incidents?
- How are patients and families involved in the response to an incident?



## 2.1 Partnering in patient safety

Safety at the point of care is everyone's business.<sup>82</sup> This means:

- Patients and families (or their advocate)
  - are actively engaged in their own care
  - are comfortable asking questions and confident in speaking up about their needs, preferences, observations, and ideas about what will improve their care safety and quality
  - take responsibility to provide accurate information to their healthcare team, ask questions to understand the information, and help develop and follow the care plan
- Providers
  - are open to suggestions and comments from patients and families
  - openly invite patients to voice concerns and ask questions. If they determine the patient's suggestion enhances safety and can be done, they are quick to adopt it and let the patient know their suggestion is being actioned. If it cannot be adopted, the provider assures the patient their suggestion has been seriously considered, and describes reasons for not implementing it, leaving the option open to reconsider the idea later
  - proactively learn and develop competencies related to engagement and safety
  - use the [Closing The Loop](#) process for patient engagement
- Organizations ensure that healthcare teams, including patients and families, have access to reliable resource materials to help them understand how safe care results from patient engagement and partnership behaviours

Engaging patients can help prevent or reduce patient safety risks by:

- Teaching everyone involved how to identify safety risks and take steps to prevent an incident
- Improving [communication](#) between patients and their healthcare providers and among providers on the healthcare team
- Involving families as care team members and encouraging their presence throughout the care journey, according to their wishes

Patients and families are involved in direct care and witness first-hand the precautions to ensure safety. They also have direct experience with how care processes can increase or reduce safety risks or affect the risk severity. They often see solutions and remedies but are commonly not asked for their ideas or to be involved in improvement. Patients and families should be invited and encouraged to provide insights about the way processes influence safety and the care experience (e.g., prescribing and giving medication, transitioning care from one unit to another and to or from home). The information provided by patients and families helps identify safety risks.<sup>49</sup>

Many studies have focused on how patients observe the way that care providers work.<sup>83</sup> Tools have been developed to guide patient observations for activities, such as hand washing,<sup>84,85</sup> medication delivery,<sup>86,87</sup> and patient identification.<sup>88,89</sup>

Patients, families, and providers need support to partner in care through an organizational culture of safety and [authentic engagement](#). Creating a collaborative climate is not easy, but it is important. By actively inviting patients and their families to speak up more often, combined with a psychologically safe environment, is essential for the encouragement of involvement in patient safety.<sup>61</sup> [Patient Safety Culture “Bundle” for CEOs and Senior Leaders](#)<sup>90</sup>, is an example of a resource meant to nourish an environment that facilitates engagement and safety.

Patients and families need to feel at ease (psychological safety) to bring up issues or observations that they have about potential harms. A culture of support and openness can help:

- Minimize fear and anxiety about potential consequences for voicing a concern about safety or reporting a patient safety incident
- Create opportunities for meaningful dialogue about preventing patient safety incidents and identifying solutions that can build safer care systems
- Help foster the expectation that anyone can and should raise awareness about a concern that might adversely affect their care or that of others

To be full partners in care, patients and families need to understand their care plan and be involved in developing it. For example, the It's Safe to Ask campaign improves health literacy, which is a person's ability to find, use, and understand health information. Low health literacy can be a major barrier to patients engaging in their care and can increase patient safety incident risks.<sup>91</sup> The campaign helps patients engage with providers by asking three questions:<sup>92</sup>

1. What is my health problem?
2. What do I need to do?
3. Why do I need to do this?

There are also important challenges engaging patients in identifying risks and patient safety incidents:

- Patients and families do not speak up because they fear it will impact their care or safety or offend providers
- Patients and families do not know how to bring up these issues with providers in a non-judgmental way
- Patients and their families may not know when to bring up their issues
- Patients and their families may not know the most effective methods for raising their concerns
- Providers are not used to inviting, receiving, and responding to feedback from patients
- Providers question feedback from people who do not have their medical training and experience
- Providers feel organizational pressure to increase efficiencies, sometimes at the expense of hearing and understanding patient concerns

Patients, families, and providers need support to work together and increase their mutual understanding about how to contribute to patient safety. This doesn't happen on its own. Evidence shows that educating and training patients and providers, ideally together, can have positive results in shifting attitudes towards partnership and teamwork.<sup>93-95</sup>

- Patients need to learn how to deliver constructive feedback to providers so that when a patient signals some potentially dangerous behaviour, the healthcare provider does not feel their competency is being questioned
- Providers need to be accountable for their actions and learn to listen to patients' concerns and build upon them to improve their practice

While it's impossible to address all patient safety aspects at once, tackling several priorities at a time can make a tremendous difference to patient safety and can help accelerate improvements. It is also important to focus efforts on organizational factors that influence point-of-care interactions. According to this [framework for safer, reliable, and effective care](#), patients and families, along with culture and a learning system, are at the core.

Priority areas for action are based on the most common patient safety incidents that occur and the actions that are most effective in reducing patient safety incidents. Most are required organizational practices included in the Accreditation Canada's Qmentum Program. Patients and families, patient partners, and the public have a role in all of them. The priority areas include:<sup>96,97</sup>

- Medication safety
- Surgical care safety
- Infection prevention and control
- Patient–provider communication
- Patient identity
- Transitions of care
- Family presence



## 2.2 Partnering in incident management

When a patient safety incident occurs, the patient and family are the immediate priority. Healthcare providers and the organization take immediate action to reduce further harm, and to provide practical and emotional support to the patient and the family. Next, patients and providers partner to figure out what happened and, most importantly, put safety systems in place so it doesn't happen again. As appropriate, the immediate response continues throughout the incident management process to promote healing, recovery, and learning.

By being engaged in this process, patients and families can help identify and generate opportunities to improve safety and reduce patient safety incidents. A patient and family's experience and insights are included in the incident analysis (e.g., through an interview) to help map out the trouble points in the care process and identify potential solutions that would make care safer. Patient partners can play a role as members of an incident review team or committee.

### Reporting

Information about patient safety incidents reported directly by patients and families is important and can help identify contributing factors. Patients and families may even know about incidents or risk factors that their health providers don't.<sup>49,98</sup>

Healthcare organizations are implementing ways to help patients to report safety incidents, separate from complaints processing. Medication incidents are reported by patients and providers to the [Canadian Medication Incident Reporting and Prevention System](#) (CMIRPS). CMIRPS collects and analyzes medication incident reports from patients, the public, providers, and organizations across the country in a standard form to understand what types of incidents are occurring and to inform system changes that will reduce future incidents.

Every organization, province, and territory has its own legislation with expectations for privacy and information-sharing after a patient safety incident resulting in harm, as well as for the public information reporting. This generally includes the degree that patients and families are provided with information after an incident and how they are included in the review of what led up to it.

The British Columbia Patient Safety and Learning System (BCPSLS) [re:act](#) is available for use by all designated agencies (under the [Adult Guardianship Act](#)) in the Province of British Columbia as a tool for tracking and managing reports of adult abuse and neglect. Each Health Authority has its own program to receive and follow-up on reports of adult abuse and neglect. Patients and families can report to re:act, see below a list of reporters:

Banker or financial advisor	Health inspector
BC Emergency Health Services (ambulance)	Healthcare provider within designated agency
BC Community Response Network	Landlord / strata
Care aide / home support	Member of the public – not otherwise listed
Community agency – not otherwise listed	Neighbour
Daughter or son	Other – designated agency
Fire department	Physician
Friend	Public Guardian and Trustee
Police	Relative – not otherwise listed
Private caregiver	Self-report by affected adult
Seniors Abuse and Information Line/ BCCEAS	Victim Link
Spouse	

Organizations welcome care-related compliments and complaints that are managed through a separate (but related) process from incident management. Every healthcare organization has its own complaints resolution process, which should be clear to everyone. The [Canadian Patient Safety Institute](#) and [Patients for Patient Safety Canada](#) offer guidance [here](#).



## Disclosure

Patients and families expect and have a right to know when something harmful or potentially harmful has happened to them. Informing them honestly, fully, and in a timely manner is the right thing to do. Patients and families want to understand what happened and share their own experience, including the impact the safety incident has had on them. They also want to provide their own insights about what went wrong, why, and actions that could have prevented it.

Disclosure describes the structured process whereby the provider openly shares information with the patient and their family after a safety incident. Disclosure leads to a dialogue that can last throughout the incident management process.

Studies have shown that only 25 to 30 per cent of physicians will disclose a patient safety incident to their patient, and often only after a patient has pressed them for details.<sup>99</sup> There are many barriers that might prevent a healthcare provider from disclosing a patient safety incident, including:<sup>100,101</sup>

- Lack of knowledge about how and when to disclose
- Concern about causing further distress to the patient or family
- Unsure how to manage the situation in the best possible way
- Fear of consequences (e.g., shame and embarrassment, being sued or losing their reputation, loss of or increased cost of liability insurance coverage)
- An organizational or professional culture that advises against or indirectly discourages open disclosure



Disclosure is a Required Organizational Practice which includes:

- ✓ Informing those affected that a patient safety incident has occurred and offering an apology
- ✓ Explaining what happened and why, as facts are known
- ✓ Discussing the immediate actions taken to care for the client and mitigate further harm
- ✓ Reviewing recommended actions to prevent future incidents
- ✓ Offering support to all involved

**Leadership 15.6**

All healthcare team members, especially physicians (as required by their professional organizations), must disclose an incident. Healthcare organizations should ensure their policies support open, honest disclosure.<sup>102</sup> To deliver this information in the most objective way possible, a pre-assessment brief is required. This takes away the personal link to any bad news the providers have to give that the patient and their families may not be ready to hear.<sup>103</sup> Some policy statements on disclosure include a commitment to apologize. In the case of a patient safety incident, the apology is about saying, “We are sorry.” The legislation protects the apology given to a patient following a patient safety incident because it cannot be used in a court of law. The expectation is that the apology is accompanied by full disclosure and meets the patient’s and family’s needs for it to be sincere and effective.

An [Apology Act](#) was introduced by Manitoba in 2007 to enable healthcare providers to apologize for harm without creating any legal liability for themselves. This legislation helps patients, families, and healthcare providers to communicate openly and honestly to help patients and their families heal from any emotional impact that the incident may have caused and rebuild trust with the healthcare provider. To date, only eight Canadian provinces and one territory (British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Nova Scotia, Prince Edward Island, Newfoundland and Labrador, and Nunavut) have developed apology legislation, or an Apology Act. The [Uniform Law Conference of Canada](#) and the Canadian Patient Safety Institute have both encouraged all provinces and territories to enact apology legislation.

Patient partners from Patients for Patient Safety Canada have shaped the *Canadian Disclosure Guidelines*<sup>81</sup> and the *Patient Safety and Incident Management Toolkit*.<sup>66</sup> The *Canadian Disclosure Guidelines* were developed in 2011 to promote a clear and consistent approach to disclosure at the individual level and in healthcare organizations across the country. These guidelines emphasize interprofessional teamwork and a culture that supports learning from patient safety incidents.

## Incident analysis

The review process (or incident analysis) to understand what happened and what actions are needed to prevent future similar incidents is an important step in incident management. It is critical for organizations to appropriately respond to and learn from patient safety incidents to make patient safety improvements in care systems.

Because harmful incidents can have serious consequences for the affected patient and family, the review process can be emotional. Practical and emotional support should be provided to patients, families, and healthcare providers involved in the incident, as well as those active in reviewing the cause and recommending a plan to prevent future harm.

Patients and families are important in incident analysis:

- The patient who experienced harm and their family can shed light on what went wrong by sharing their experience and, if they choose, advocating for changes in the organization
- An experienced patient partner can offer the patient’s perspective as a member of an incident analysis review team

Research and practice are revealing powerful reasons for seeking patient and family input, even from patients directly involved in the safety incident, such as the following:

- Patient and family input pushes providers to think about alternative perspectives
- Patient insights into the circumstances of the incident can shed greater light and lead to a deeper analysis of the underlying cause(s)
- A patient’s practical knowledge can provide insights into possible improvements and solutions to prevent further incidents (e.g., “The family advisor came up with the most interesting part of the action plan.”)

Patient safety incidents are analyzed to help prevent recurrence and make improvements, with input from clients and families.

Child, Youth, and Family  
Services 14.10



Leading and emerging practices suggest two ways that patients and families should be involved:

1. In the incident, patients and families are:
  - Informed about what happened and what will be done through the disclosure process
  - Interviewed to inform the incident analysis
  - Kept updated about recommended actions
  - Asked to participate further
2. In incident analysis and management, patient partners:
  - Receive training and information about the incident analysis process
  - Participate on teams that carry out structured incident analysis
  - Participate on a quality and safety committee that oversees monitoring and improvement at the organizational level, including follow-up from incident reviews

## 2.3 Summary - What you can do



### Patients, families, and patient partners

For your safety and the safety of others:

- Actively participate in your own care and treatment, especially during care transitions
- Share information, concerns, and suggestions
- Learn how to reduce safety risks while at home and in the community

If you or a loved one has experienced unanticipated harm:

- Ask what happened, why, and what will be done about it
- Seek out the proper way to report the incident
- Expect an apology and to be informed about next steps
- Ask for practical or emotional support to cope with the incident
- Inquire about additional support if you feel you are not getting the answers you need
- Share ideas, concerns, and suggestions to improve the incident management process



### Providers, patient engagement specialists

To advance patient safety in partnership with patients:

- Ensure patients and families actively are engaged in their care and decision-making
- Ensure patients and families are comfortable voicing concerns and asking questions
- Educate patients and families about patient safety, especially those most vulnerable
- Listen closely to patients and families, as they are all unique
- Make sure information is accurate and understood by patients and families
- Participate in and encourage open sharing and team learning about patient safety risks

If you are involved in a patient safety incident:

- Follow the organization's procedures, practices, and guidance for reporting, disclosure, and incident management
- Learn about, access and/or request practical and emotional resources and support



### Leaders

- Ensure your organization's policies, processes and resources for patient safety and incident management are used
- Ensure your organization's policies are visible to patients and their families
- Revise policies to ensure that workflow and patient-provider encounters are designed to improve the safety of the care journey, connectedness and trust<sup>104</sup>
- Ask everyone involved in a patient safety incident about their experience and recommended actions for improvement
- Share patient safety and incident management information across the organization and incorporate improvement ideas into policies, procedures, and training
- Ensure timely, honest, and transparent communications with patients, families, and providers.
- Visibly value and support patient engagement in patient safety and incident management
- Strive towards a safe and fair culture that is centred on patients and families

## 2.4 Practice examples

### Patient engagement to prevent harm (Safety alert/Stop the line) Saskatchewan

[Safety Alert/Stop the Line](#) invites patients and expects staff and physicians to be safety inspectors, to identify and fix potentially harmful mistakes in the moment, or to “stop the line” and call for additional help to restore safety. Saskatchewan is implementing this initiative to strengthen the safety culture and make healthcare environments safer for patients, staff, and providers. The initiative includes processes, policies, and behavioural expectations. Research shows that organizations that experience close to zero safety incidents (called high reliability organizations) demonstrate Safety Alert/Stop-the-Line’s effectiveness. The goal of Safety Alert/Stop the Line is to eliminate harm to patients and staff by 2020.

The approach is based on everyone taking responsibility for making healthcare settings **SAFER**:

Stop if you see something that is unsafe.

Assess the situation. Ask for support from others, supervisors, or leaders.

Fix the unsafe situation if you can. If you can’t, then...

Escalate your concern. Call in help from a team member or leader.

Report unsafe situations, environments, and practices, including both instances of no harm and incidents that have resulted in harm to patients or staff. We can’t improve what we don’t know about.

The Saskatoon Health Region is testing the value of a 24/7 call centre to report safety incidents. Similar to 911, this one phone line is used to report all safety incidents and is for everyone’s use (patients, families, staff, and physician).

For more information about a co-design project that involves patients and staff in identifying safety alerts, including patient and provider stories, watch this Saskatoon Health Region [video](#).

#### Case Study: McGill University Health Centre [We Should Talk Campaign](#)<sup>105</sup>

The McGill University Health Centre (MCH) case study highlights how an organization fostered grassroots improvement ideas from frontline clinicians in order to improve patient involvement and patient safety. The *We Should Talk Campaign* brought together a multidisciplinary team to improve patient and family, as well as provider awareness of the importance of speaking up and listening when concerns are raised. The campaign aims to influence both patient and provider behavior through improved communication, promoting a culture of safety. The campaign uses a framework called the Mutual Learning Model, a series of workshops as well as a number of practical tools, which help to promote how to speak up effectively, and how to become better listeners when someone expresses a concern or a question.

Assistance aux antimicrobiens  
Comité permanent de la santé de la  
Chambre des communes  
Le 7 novembre 2017  
Neil V. Rao, M.D., FRCPC  
Spécialiste en maladies infectieuses et microbiologiste  
medical  
Professeur adjoint, Département de médecine, Division  
des maladies infectieuses, Université de Toronto

# Partners at organizational and system levels



## 3. Partners at organizational and system levels

“Putting patients in positions of real power and influence and using their wisdom and experience to identify issues and to inform and re-design care... provides the most important force for driving change and has the greatest potential for achieving long-term transformation in the healthcare system.”<sup>106</sup>

Safe care is critical for patients and families, providers, and organizations. To realize improvements in care safety, healthcare organizations and providers need to partner with patients in all aspects of patient safety, from prevention to incident response.

Partnering with patients and families for quality and safety in organizations and systems helps:

- Inform changes to processes and policies that shift to safer, more patient-centred care
- Build structures and processes for safer, better quality care

This chapter offers guidance, tools, and practice examples that support patient and family partners to take on roles in safety and quality, helping organizations prevent, respond to, make improvements, and learn from patient safety incidents.

## 3.1 Preparing for patient engagement

“It brings us back to the deeper meaning of what we should be doing in a health organization. We talk a lot about our patients, and we work for the patients, but now we do things with the patients, and that changes the dynamic.”<sup>93</sup>

### People - roles and responsibilities

Many people may come together to partner in quality and safety improvement processes. Patient partners, specialists, and providers each bring a unique role and perspective, but share responsibility for working together in partnership effectively.

#### Patient partners

Patients are experts in their illness and care experience. Their experiential knowledge and perspectives are critical in improving quality and safety processes.

Successful patient partners are:<sup>107</sup>

- Respectful of others and their perspectives
- Comfortable speaking in a group and working with others
- Good listeners
- Able to use their personal experiences constructively, seeing beyond their own experience
- Non-judgmental
- Able to work collaboratively with other patients, families, and healthcare providers
- Interested in expanding their knowledge and skills
- Committed to helping bring about meaningful change

**Patient partner:** an individual who experienced care in the healthcare system (as a patient, family member or caregiver) and who, as part of a patient group (e.g., patient and family advisory council), engages in shaping decisions, policies and practices at all system levels. Other terms used include advisor, leader, or champion.

Patient partner participation can range from sharing personal care experiences to providing feedback and testing materials or processes. They may help determine what went wrong and why and contribute the patient perspective to specific improvement initiatives (e.g., reducing falls in seniors’ homes, improving the discharge process to prevent readmission). Patient partners may participate in any healthcare setting (e.g., local health authority, acute care hospital, long-term care institution, residential home).

Some organizations have a permanent structure to help identify priorities that matter to patients and families and to provide a sounding board for providers who are developing new policies, programs, or improvement initiatives. In most settings, these are called patient and family advisory councils (PFACs). In residential settings (e.g., seniors’ homes or long-term care facilities), they’re often called residents’ council or family council.

Roles presented in the following table could be filled by an established advisory council. These permanent councils provide early experience to a family partner and lead to their deeper involvement in quality and safety processes in the organization (e.g., incident analysis, quality and safety committee, quality improvement team). In other cases, patient partners may not have been involved with these types of formal patient engagement structures.

## Examples of patient partner roles

Adapted from [Partnering to Improve Quality and Safety: A Framework for Working with Patient and Family Advisors](#)<sup>108</sup>

Committee/work group to develop educational and communication materials	<ul style="list-style-type: none"> <li>• Help identify information needs or gaps in existing materials and tools</li> <li>• Co-design content and format of materials</li> <li>• Identify language or materials that are confusing or unhelpful, and determine if materials are well-formatted and helpful</li> <li>• Assist with testing and adjusting the materials</li> <li>• Follow up with other patients to gather their opinions</li> </ul>
Incident analysis	<ul style="list-style-type: none"> <li>• Share a personal story to ground the team in the lived experience of the patient and family</li> <li>• Identify pieces of the process that are confusing or missing from a patient and family perspective</li> <li>• Participate in information/data gathering</li> <li>• Discuss and analyze findings</li> <li>• Assist in developing action plans and recommendations</li> </ul>
Discharge planning	<ul style="list-style-type: none"> <li>• Help design new materials</li> <li>• Review the materials and process from the end-user's (patient's) perspective</li> <li>• Participate in rounds</li> <li>• Assist in piloting new materials</li> </ul>
Quality and safety committee	<ul style="list-style-type: none"> <li>• Bring the patient and family perspective into discussions</li> <li>• Collect feedback from other patients about specific issues (e.g., when outside one's own experience)</li> <li>• Help interpret and analyze patient experience data</li> <li>• Question the assumptions of practitioners that differ from the patient and family experience</li> </ul>
Process improvement teams	<ul style="list-style-type: none"> <li>• Serve on improvement teams with patient safety goals (e.g., engaging patients and staff in identifying safety risks, reducing preventable readmissions, medication incidents, falls and infections)</li> <li>• Review materials related to improvement initiatives</li> <li>• Help test and adjust new quality and safety processes</li> </ul>

The following table provides additional examples of patient engagement in primary care practices. These examples were collected from a survey of 37 community health centers as well as from people working in the field.<sup>109</sup> Some of these examples are also used in other settings as they can be adapted from one healthcare setting to another.

Examples of patient partner roles in primary care practices <sup>109</sup>			
Strategy	Description	Advantages	Limitations
Complete patient surveys	One-time surveys given to patients to assess experience of care or components of care delivery	Quick, low cost	Unidirectional, may not capture the right data, limited response
Use the suggestion box	Comment boxes in waiting rooms or exam rooms to collect ideas for practice improvement projects	Ongoing, can help to generate new practice improvement ideas	Typically, low participation, needs upkeep to maintain and collect responses
Be a secret shopper	Patients gather experiential feedback from trial phone calls to clinic or gathering step-by-step feedback on each step of clinic visit	Quick, low cost, can feed into patient experience efforts	Hard to recruit patient volunteers, data may not be representative
Attend a town hall	Large-scale forum to gather community feedback on clinic initiative	Modest cost, if participation is high gains a large pool of feedback, patients can interact/discuss with each other at meeting	One-time feedback, may be challenging to facilitate

Examples of patient partner roles in primary care practices <sup>109</sup>			
Strategy	Description	Advantages	Limitations
Be a partner on a quality improvement (QI) team	Patients are QI or practice improvement team members	Project driven, aligned with clinic QI efforts	Patient is minority among staff, may not feel supported in participating, not necessarily representative feedback
Join providers at conferences/workshops	Patients accompany staff/clinicians to academic or practice-based meetings to share experiences	Provides visibility to patient partners, patients may have unique insights to inform organizational priorities	Limited amount of patient representation, may not have clear follow-up for clinic operational improvements
Become a member of a patient advisory council	Representative group of seven to 15 patients who meet monthly or quarterly to discuss practice improvement	Bi-directional feedback, project driven, can recruit diverse/representative council, can integrate with QI efforts at the clinic	Time-intensive, higher cost, require staff time, can be hard commitment for patients
Assist in training providers	Patients participate in onboarding and training new clinical staff, particularly in-patient communication	Demonstrates importance of patient perspective to new hires, builds awareness for patient experience of care	Patient partners need support and role clarity within training
Participate in a virtual advisory board/social media opportunity	Use online message boards and social media to collect patient feedback, project-oriented patient working groups that exist for shorter term	Nimble, more action-oriented, may access harder-to-reach patients, such as teens or younger working families	Less tested, some concerns about online security

## Patient engagement specialists

Effective partnerships between patient partners, providers, and organizations in safety and improvement initiatives are enabled by patient engagement specialists. Their role is to connect stakeholders, prepare them to work together, provide expertise, knowledge, and tools to do the work, and help them learn from the experience.

Specialists should know the principles of patient and family-centred care, and have engagement methods, tools, and skills to coach patients, families, and providers to work together effectively.

Patient engagement specialists or staff:<sup>110</sup>

- Are friendly and welcoming
- Believe in the importance of the patient perspective
- Understand meaningful engagement
- Are transparent and open
- Listen and communicate well
- Know how to build trusting relationships
- Demonstrate patience and persistence
- Are creative and flexible
- Collaborate
- Provide strategic leadership by linking patient engagement with the program or organization

Depending on the organization’s experience, patient engagement specialists have different titles and may do the work as part of other responsibilities (see the following table). Some organizations have hired patients and families to help carry out patient engagement activities.

Examples of staff responsible for patient engagement	
Dedicated staff position	Support as part of broader staff role
<ul style="list-style-type: none"> <li>• Patient engagement specialist</li> <li>• Patient partnership program coordinator</li> <li>• Patient and family-centred care coordinator</li> <li>• Patient engagement advisor</li> <li>• Patient experience lead</li> <li>• Client and community relations coordinator</li> </ul>	<ul style="list-style-type: none"> <li>• Staff liaison: links patient and family advisory council with the organization</li> <li>• Administrator (in smaller organizations): provides support to a patient council</li> </ul>

Patient engagement specialists also connect with patient safety and quality improvement specialists. To succeed, they should have formal and informal linkages (e.g., both are part of the same team, attend meetings) with providers and leaders who support quality and safety improvement processes.

Quality improvement specialists:

- Have complementary methods and tools to help teams work collaboratively to identify patient safety improvement areas, explore, test, and implement solutions to build safer care processes
- Know where to find evidence-based best practices that have been shown to improve safety and quality of care
- Connect with communities of practice that are trying out new approaches and sharing what they have learned

Patient engagement specialists and quality and safety improvement specialists can work together to:

- Recruit and prepare patient partners and staff to participate meaningfully
- Define respective roles in the improvement initiative
- Support team collaboration and ensure that the process and result are influenced by the contributions of patients, families, and providers
- Share initiative results

## Providers (clinicians, non-clinicians, clinical leads)

Providers who partner with patients in quality are change agents in the organization. They may be leaders (clinical leads), clinicians, or non-clinicians on a team or supporting the effort.

Clinicians (e.g., physicians, nurses, rehabilitation therapists) offer:

- Medical knowledge and experience
- An understanding of how care processes work within the broader organization’s care system
- Information about clinical guidelines and best practices
- Knowledge of the constraints on care delivery (e.g., ethical and professional practice requirements, costs associated with equipment, human resources)
- Access to leaders in the organization to mobilize support for testing new solutions and implementing successful changes

Non-clinicians (e.g., administrative staff, managers, support personnel like housekeeping and porters) offer unique perspectives that are eye-opening and invaluable in redesigning safer care processes. They may participate in quality and safety improvement processes, particularly when changes relate to how information is recorded and shared among:

- Care team providers
- Different departments
- Different healthcare organizations across the continuum of care

Some providers are partnering with patients and families to make improvements and champion patient engagement. They share how patients have brought new knowledge about how the care processes work and feel for them, not just how they are supposed to work. Patients and families may bring new solutions that clinicians haven't considered to make care processes safer and deliver more patient and family-centred care. Through dialogue, everyone can learn about the concerns and develop a mutual understanding.<sup>93</sup>

Providers partnering with patients and families:<sup>111</sup>

- Believe the patient and family perspective matters
- Contribute to creating a trusting space for open and honest discussion
- Are respectful and non-judgmental
- Communicate with all members of the team or committee as equals and use common terms (clarifying medical terms when needed)
- Seek out, value, listen to, and explore everyone's ideas and perspectives
- Are aware of how others perceive their communication style
- Bring a collaborative, problem-solving spirit that invites new ways of working together and understanding issues

Education and training are provided throughout the organization to promote and enhance a culture of people-centred care.

Leadership 10.4



Patient engagement in safety and quality is still not common in every organization. One of the challenges is the readiness of providers to partner which is shaped by their perception of the value of patient engagement. [The Readiness to Partner](#) tool is an example of a resource to assess providers' capacity to partner with patients and to identify actions for improvement.

## Planning for partnership

Meaningful patient engagement does not happen on its own; it needs to be carefully planned. Planning is more effective when patient partners are engaged at the beginning of the process, even when it feels a bit messy.

Partnering involves using methods and tools from different domains (e.g., patient engagement, quality improvement, project planning, and communications) to/for:

- Clarify purpose
- Choose the methods for engagement
- Recruitment and orientation
- Preparation and support

## Purpose clarity

Effective engagement begins with purpose clarity. Knowing why you are engaging people and what you hope to

achieve is critical for developing clear partnership expectations. To achieve clarity:

- Describe the purpose of the partnership to ensure that everyone involved, now and in the future, has a shared understanding of the goals. At this stage, avoid pre-determining solutions and seek clarity about the problems to address and desired benefits, incorporating all perspectives. For example, are you:
  - Identifying or implementing better ways to track and monitor patient safety incidents?
  - Developing or improving a process to identify safety risks and to reduce the likelihood they will occur?
  - Responding to and understanding what happened after an incident and to identify solutions?
  - Proactively taking steps to improve a policy, care process, or system to make it safer?
  - Changing culture, attitudes, and behaviours to improve safety?
- Articulate your commitment to partner meaningfully to avoid setting false expectations:
  - Make patient partners feel welcomed and that their participation is valued as necessary and useful
  - Invite honest feedback and input about programs and services that patients and families have used or continue to use
  - Support providers to listen with curiosity and compassion
  - Incorporate patient partner input and ideas into project developments and final decisions about programs and services
- Identify measures early on to help monitor engagement and work progress and outcomes

Use a “[What Matters to You?](#)” approach where, as a healthcare provider, you start a conversation with your patient by asking them what really matters to them. This helps with building trust, developing empathy and better understanding of your patients, ultimately improving the quality of care provided.<sup>112</sup>

## Choosing engagement methods

Patient engagement may look different, depending on engagement reasons and goals. Involve patient partners early in engagement activity or project planning to help ensure success. The purpose and people will help with selecting the right engagement methods (e.g., survey, focus group, committee member) and level (e.g., inform, consult, or collaborate).

Each engagement method has its benefits. Different methods can be used at different stages, depending on the setting, time available, skills, and budget. Using multiple patient engagement methods and creatively adapting them to the context helps ensure perspective diversity and inclusion. This is to ensure that all populations, including the most vulnerable and marginalized, can see themselves within the efforts of heightened engagement.<sup>113,114</sup>

Patient partners engage in safety and quality in different ways, including one-way input to share their lived experience (e.g., through sharing stories, being interviewed, or completing a survey). In many cases, patient partners are equal partners on teams or committees to co-design care with providers.<sup>115</sup>

Learn about peoples’ expectations, interests, and influence in relation to the purpose. Stakeholder engagement [tools](#) help map out this information and determine the right level of engagement for the right people.<sup>116</sup>

## Key elements for a healthy engagement ecosystem:<sup>117</sup>

- Building local and national “hubs” to facilitate learning and capacity building across engagement domains; populations and contexts (e.g. [Patient Alliance for Patient Safety](#));

- Supporting reciprocal partnerships based on co-leadership; and
- Strengthening capacities for research, evaluation, and co-training of all partners to support reflective engagement practices that bring about effective change

## **Recruitment and orientation of patient partners**

A structured process for recruiting and orienting patients to the patient partner roles includes:

- Inviting the patient partner to complete an application form. The form collects basic demographic and experience data, and asks about their main motivations for becoming a patient partner
- Conducting an in-person or telephone interview to assess fit for the patient partner interests, their availability, and organizational requirements
- Completing organizational requirements (e.g., signing a confidentiality agreement or a police record check)
- Matching the new patient partner with an experienced partner for mentoring or coaching
- Orienting the new patient partner. Some topics that might be covered include the patient partner role, the organization’s approach to improving safety and quality, and the history of the team or committee.
- Providing culturally appropriate training on specific skills that will help them succeed (e.g., understanding the importance of storytelling when interacting with Indigenous patients)

Strengthen recruitment efforts by engaging patient partners who can:

- Provide input into the role description
- Help identify where to find potential participants and the best methods
- Make presentations at patient and family groups to explain the opportunity and encourage people to get involved
- Reach out in their own networks
- Answer questions for people who may be interested but want to hear first-hand from someone who has been involved

## **Aim for equity, diversity and inclusion<sup>114</sup>**

- For patient engagement to be effective in shaping healthcare service design and delivery, those involved need to reflect the diverse lived experience of the people the organization serves and the broader community.
- Providers need to deliver culturally appropriate healthcare and be sensitive to social, language, and cultural differences and preferences. Social and cultural background affects a patient's care experience in many ways, including ways that can impact patient safety.
- To increase diversity, consider the following characteristics:
  - Age, sex/gender, income variety, education, differing neighbourhoods, and/or disability
  - Languages, ethno-racial communities, and cultures
  - Lifespan perspectives (e.g., elderly vs. young family)
  - Family structures and roles (e.g., single, married, caregiver, friend).
  - Different experiences with health issues and healthcare
- Consider barriers that different groups may have to participating:
  - Avoid recruiting only those with certain capacity, skills, and experience (e.g., being articulate, well educated, able to represent others from their group)<sup>118</sup>
  - Use different outreach and engagement methods to include those who are not typically involved or are more vulnerable or marginalized.

To learn more about why diversity matters, types of diversity, removing barriers to participation, tips and tools for reaching out, and case examples, see Health Quality Ontario's [Recruiting for Diversity](#) and Cancer Care Ontario's *Equity in Engagement Framework and Toolkit* (includes a framework to promote and prepare for equitable engagement, a process within the framework to create engagement, and considerations and opportunities for working with specific populations).<sup>113</sup>

Providers, leaders, sponsored groups (e.g., cancer survivor support group, online forum for new mothers), organizational web pages, newsletters, and social media posts can all help with outreach.

The [Alberta Health Services Patient Engagement Toolkit](#) includes a self-assessment tool to help potential patient partners think through their strengths, attitudes, and other practical interview considerations (e.g., who should be involved, how to set up the interview, sample questions). Be sensitive to when individuals may not be ready for patient partner roles (e.g., individuals who have experienced harm and may be at risk for being re-traumatized). Other tools, such as [Patient Decision Aids](#) can assist patients in making complex health decisions, leading to better treatment outcomes.<sup>119</sup>

Building capacity for partnership can shape an organization's culture. To do this, include patient engagement, people-centred care, and their link to quality and patient safety in orientation programs.<sup>120</sup> Experience shows that it is essential to train everyone involved to partner effectively.

The University of Montreal trains patient partners and providers to collaborate on quality improvement initiatives. The training is co-led by a patient and provider and focuses on building the competencies needed for effective patient partnership and collaboration, such as:<sup>111</sup>

- Understanding roles and responsibilities
- Developing shared goals
- Organizing effective meetings
- Communicating effectively
- Leading collaboratively
- Evaluating the partnership together

## **Preparation and support for patient engagement in patient safety**

Selecting patient partners for patient safety initiatives begins with clearly describing the required skills and experience.<sup>108</sup> This is done by the people leading the initiative, team, committee, or those designated to bring patient partners on board. Whenever possible, look for patient partners with program, service, or care-process experience. Provide them with clear expectations, participation benefits, available supports, and a primary contact.

Established patient and family advisory councils are usually the first place to look for patient partners, but they might not include members with the required skills and experience. You may need to look elsewhere, which also helps overcome the tendency to work with the same experienced patient partners on multiple projects. Patient partners may burn out and diversity is always beneficial.

### **Preparing patient partners**

To ensuring a good fit between patient partners and an engagement opportunity:

- Clarify the background, experience, and/or skills needed to participate
- Specify the type and extent of participation (e.g., tasks, expected contribution, duration, location, other stakeholders involved)
- Develop a recruitment strategy and provide training and orientation. Consider:
  - Do people need to have personally experienced a health condition, specific care process, program, or unit?
  - Could the participation cause harm? (e.g., Will the incident analysis trigger difficult memories or emotions?)
  - Do people need specific experience, skills, or training to participate meaningfully? (e.g., knowing how to reflect on their own experience and think about what it means for improving care processes or systems).
  - What diversity will accurately reflect the people affected by the care process, program, or service?

## Checklist: preparing patient partners for work on committees, workgroups, and teams<sup>108</sup>

Information to share	Topics to cover
<b>Terms of reference</b>	<ul style="list-style-type: none"> <li>• Purpose</li> <li>• Goals and objectives</li> <li>• Duration (if not an ongoing committee, work group, or team)</li> <li>• Frequency of meetings</li> <li>• Confidentiality</li> </ul>
<b>Decision-making</b>	<ul style="list-style-type: none"> <li>• Process for setting the agenda</li> <li>• How decisions are made (e.g., rules, voting, consensus)</li> </ul>
<b>Membership</b>	<ul style="list-style-type: none"> <li>• List of members and their background</li> <li>• Roles and responsibilities (e.g., who chairs the meeting)</li> </ul>
<b>Background</b>	<ul style="list-style-type: none"> <li>• Accomplishments to date</li> <li>• Barriers</li> <li>• Record/minutes of recent meeting(s)</li> </ul>
<b>Progress</b>	<ul style="list-style-type: none"> <li>• Upcoming agenda items</li> <li>• Success measures</li> <li>• Any priority shifts</li> <li>• Strategic objectives</li> </ul>
<b>Background information</b>	<ul style="list-style-type: none"> <li>• Current research</li> <li>• Relevant policies and protocols</li> </ul>

Handbooks help orient patient partners to their role, with tips on:

- How to prepare for and how to participate in meetings
- Using their voice effectively to make change
- The difference between debate and dialogue
- Understanding the dimensions of patient experience

Depending on the patient partner's role, clarify when [sharing a personal story](#) is appropriate and helpful and when they need to move beyond it to focus on and provide input into the improvement work's goal. Participating on a quality and safety improvement team or committee is unique from other patient partner roles and requires additional preparation and support for patient partners. (See the following table.)

## Preparing for the partner role on a quality and safety improvement team or committee<sup>108</sup>

- Explain jargon or acronyms commonly used by the team or committee and encourage patient partners to speak-up when they do not understand
- Prepare patient partners for the clinical manner in which providers may discuss patients or disease progression. It may seem harsh or insensitive
- Check-in early and often to find out how patient partners are reacting to what they are hearing
- Provide general training on quality improvement methods and explain the organization's specific approach. Mention current quality and safety issues and priorities in the organization. Having some background will help the patient partner become an active member of the team

Consider also:

- Having patient partners participate in the same training that staff receive
- Creating basic training tailored to patient partners and their role
- Identifying a mentor or coach who can help prepare and support the patient partner. This could be another provider on the team or committee, a quality improvement specialist or coach, or an experienced patient partner.

## Preparing providers and leaders

As patient engagement on teams or committees becomes more common, providers and leaders also need to prepare for their role. The following table offers guidance for leaders and others supporting providers in the partnership.

Preparing providers to work with patient partners <sup>108</sup>	
Consideration	Description
Link patient partner involvement to specific goals and objectives	<ul style="list-style-type: none"> <li>Identify how patient partners have contributed to the objectives of the committee, work group, or team</li> <li>Show that patient partners are valued as integral members</li> </ul>
Provide opportunities for staff members to ask questions, express concerns, and give feedback	<ul style="list-style-type: none"> <li>Concerns might be about:               <ul style="list-style-type: none"> <li>Health information privacy and confidentiality</li> <li>Fit and culture</li> <li>Impact on existing work processes</li> </ul> </li> <li>Keep communication channels open to:               <ul style="list-style-type: none"> <li>Catch any concerns early in the process</li> <li>Build a culture of transparency and acceptance</li> </ul> </li> </ul>
Provide a mechanism for ongoing feedback	<ul style="list-style-type: none"> <li>Periodically check in with staff members to:               <ul style="list-style-type: none"> <li>Evaluate how the partnership is working</li> <li>Address any barriers as necessary (typically done by committee chair)</li> </ul> </li> </ul>

Providers should engage with patient partners as equal members of the safety and improvement team or committee. Providers might consider them “honoured guests” and give them special treatment. Instead, patient partners should receive the same professional treatment and expectations as any other team or committee member. Remembering that a patient partner is a full member of the team leads to a more successful partnership.

Team or committee members should be reminded that this is a unique and, for some, a new experience:

- Patient partners may need time to feel comfortable. All members should understand each other’s perspectives and experiences (e.g., harm event or other distressful experience) to partner effectively.
- Providers might need more information about the benefits of including the patient and family perspective and how the process worked for other teams or organizations. Share information in advance about the patient partner’s background, their training and experience, and about the team or committee members.
- Being explicit about ground rules may help reduce defensiveness and allow members to truly listen to understand one another’s experiences. These can be established ahead of time or as part of the group’s process.

For team or committee chairs or clinical leads, create supportive, positive, constructive working relationships through:

- Briefing the patient partner before and after meetings to share information, answer questions, and check in on any hesitations or concerns
- Keeping patient partners informed
- Inviting input from everyone, ensuring that partners have a structured opportunity to share their perspectives and ideas

Ensure information privacy and confidentiality, which is a common concern for providers, through:

- Providing patient partners with the same training on these issues as other members of the team or committee
- Creating guidelines for information-sharing and confidentiality
- Taking steps to de-identify sensitive information when appropriate
- Real-time reminders (e.g., at the end of each email)

Other best practices for supporting partnerships on teams or committees include:

- Including two to three patient partners
- Identifying a primary contact to help prepare and stay informed
- Providing different ways to participate (e.g., virtual, in-person, in writing)
- Paying attention to logistics and practical support (e.g., meeting times, location, expenses)
- Offering a mentor for new patient partners and working with them to identify training and support needs, including emotional support
- Bringing patient and family stories of their care journey into discussions about safety and quality.<sup>108</sup> When meetings open with a patient experience, it helps to:
  - Ground discussion in this critical truth – that care safety and quality has a very personal and very direct impact on patients and families
  - Motivate members to find solutions and make changes
  - Unearth the contributing factors for the problem and the specific points in care where solutions are needed to improve safety and quality<sup>121</sup>

## 3.2 Partnering in patient safety

“First do no harm.’ This principle remains central to the provision of high-quality healthcare. The mission to make care safer unites professionals and patients alike, and safety is a key component of any quality initiative.”<sup>122</sup>

Patient partners are linked to the following two safety and quality processes:<sup>66</sup>

- Patient safety management: The actions that help to proactively anticipate patient safety incidents and prevent them from occurring. These include managing patient safety risks, co-designing and testing safety solutions, and quality improvement processes. Patient safety incident reporting, quality, and safety committees, monitoring and reporting on safety and quality outcomes and quality improvement initiatives all work together as part of a learning system.
- Incident management: The actions that follow patient safety incidents (e.g., near misses), including immediate response, disclosure, incident analysis, implementing actions to reduce risk of recurrence, and sharing learning.

Patient engagement in patient safety and incident management needs to move beyond pilot projects to a more strategic approach<sup>55</sup> and be structured into an organization’s quality and project management processes.<sup>123</sup>

### Patient engagement in patient safety

Patient engagement in preventing harm and maintaining care safety:<sup>121</sup>

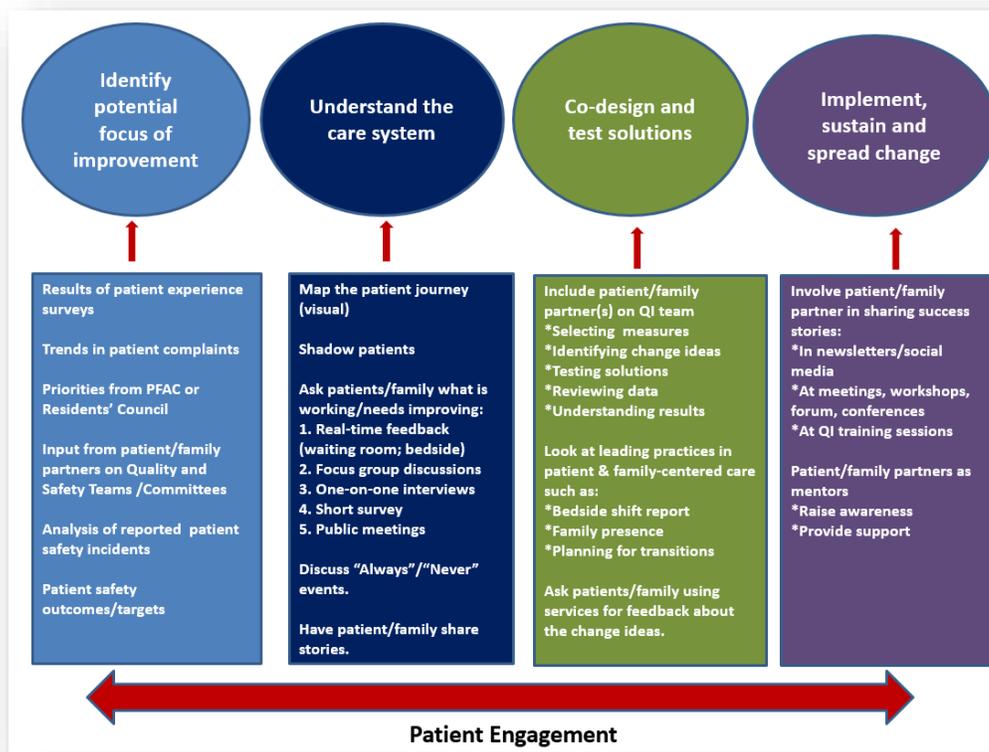
- Provides insights and ideas for quality improvement efforts
- Challenges assumptions
- Improves communication between patients and providers
- Motivates providers to make changes by seeing them from the patients’ perspectives
- Ensures that patients are full participants in decisions that affect them
- Empowers patients to become active partners in their own health care
- Results in meaningful changes to healthcare services

Patient partners<sup>124</sup> help prioritize, develop, and review organization-wide [quality and safety plans](#) by:

- Participating on the quality and safety committee responsible for developing the plans and reports to the board
- Providing input into plan development through the patient and family advisory council or another patient group
- Reviewing the plan’s progress reports and providing guidance on reaching the targets or new priorities
- Participating in focus groups or town hall meetings to provide feedback on the plans
- Getting involved in planning and implementing the quality improvement and change activities described in the plan

The following figure (adapted from Alberta Health Services and Health Quality Ontario) summarizes the steps in the quality improvement process with ideas for patient engagement.

## Patient engagement in improving quality and safety



### Identify potential focus for improvement

Areas for patient safety improvement can be identified by examining existing patient or family input, including:

- Patient complaints data
- Patient experience surveys
- Incident reports that include reports from patients
- Incident analysis findings
- Quality and safety improvement plans

If required, engaging patient partners helps gather more information about designing effective tools and processes, outreach, collecting information, and compiling results through:

- Real-time feedback at the point of care (e.g., waiting room, bedside rounds, at discharge)
- Focus groups or town hall meetings
- One-on-one interviews
- On-line patient forums
- Meetings with the patient and family advisory council (or local equivalent)
- Strategic planning meetings where patients, families, and providers provide feedback to better deepen understand challenges and improvement opportunities

Organizational needs assessment tools, such as the [Person and Family Centred Care](#) from Saint Elizabeth Health Care (aligned with many of the people-centred care requirements in Health Standards Organization) can help focus your efforts.

Patient partners who help identify potential improvement focus areas may not be the same people engaged in other steps. This is a good opportunity for those interested in participating in other steps of the improvement process (e.g., understanding the system of care or being involved in co-designing and testing solutions).

## Understanding the care system

Early in the improvement process, develop a good understanding of what works and what doesn't in the full care journey.<sup>125</sup> Ways to engage patients include:

- Helping create a visual map of the patient journey
- Providing real-time feedback about the experience of care (e.g., in the waiting room, at the bedside)
- Participating in focus group discussions, one-on-one interviews, or public meetings.
- Completing a survey (e.g., paper, on-line)
- Sharing patient and family stories with the improvement team or committee

Patient partners together with the improvement team [set goals and measures](#) that are meaningful to patients and will impact care outcomes. The [Picker Institute in Europe](#) identified these dimensions of quality that are important to patients and families, and can impact the safety of their care:<sup>126</sup>

- Relationships and communication:
  - Involvement in decisions/respect for preferences
  - Clear information and support for self-care
  - Emotional support, empathy, respect
- The healthcare service/system:
  - Fast access to reliable healthcare service
  - Effective treatment by trusted professionals
  - Attention to physical and environmental needs
  - Involvement of and support for family/caregivers
  - Continuity of care and smooth transitions

## Co-designing and testing ideas and solutions

Engage patient partners and others who can provide useful input into possible change ideas, including:<sup>121</sup>

- Brainstorming change ideas to provide a useful perspective on what change matters most. Often patient suggestions are the 'low-hanging fruit'.
- Asking patients who have had difficult experiences in the system or who have experienced harm about what could be done to avoid the problems in the future.

Respect patients' perspectives and communicate if suggestions are not within the scope of the project or are not feasible. Solutions should consider leading practices in people-centred care that improve safety and quality of care (e.g. bedside shift report, family presence policies, and patient engagement in [planning for transitions](#)).

When testing changes, ask patients and families currently using services for feedback about the change ideas. After they are implemented, seek out feedback on how the changes are



making a difference to the experience of care.

There are synergies between patient engagement and quality improvement approaches. Patient engagement and quality improvement specialists can work together to bring the experiences of patients and family into improvement processes and increase the potential for success.

Combining quality improvement tools and science with the art of purposeful, meaningful patient engagement is optimal. Sometimes engagement methods or tools can be built into the quality improvement process to fill gaps (e.g., using video to increase understanding of vulnerable people, such as elders, palliative patients, and those with multiple chronic conditions who are not well represented in focus groups and advisory councils.<sup>127</sup>

Experience-based co-design (EBCD) connects providers, patients, and families to collaborate, identify, and implement improvement projects. This is preceded by a careful process to capture and understand the experiences of patients and front-line providers.<sup>128,129</sup> Specific EBCD tools include:

- **Interviews:** individual interviews with patients, families, and staff to capture care experiences
- **Touchpoints and emotion map:** emotionally significant moments during patient care journeys depicted visually using an “emotion map”
- **Video:** clips from patient and family interviews that depict collective experiences for a specific care process and highlight emerging themes
- **Feedback events:** individual group or joint events held with staff, patients, and families to deepen understanding of care experiences and identify improvement areas
- **Co-design events:** meetings with patients, families, and staff to develop solutions to the problems identified during the feedback events
- **Surveys:** EBCD participants surveyed after events to monitor engagement quality and processes and capture insights that may not have emerged during group activities

## Implementing, sustaining, and spreading change

Change management approaches that reach both the rational brain and the emotional brain can help increase the likelihood that providers and patients will change behaviours. Patient partners help implement, sustain, and spread successful changes within the healthcare organization and more broadly. Involve patient partners in sharing success stories that highlight improvements in safety (e.g., through newsletters, social media, by co-presenting at meetings, workshops, conferences, and at QI training sessions). Patient partners can:

- Make an emotional connection through stories and examples
- Help providers overcome barriers to adopting changes
- Serve as mentors
- Help raise awareness about the changes
- Motivate and support all involved
- Guide other patient partners who are new to improvement processes

Encouraging evidence that patient engagement is a worthwhile investment is presented in the 2018 report *Strategically Advancing Patient and Family Advisory Councils in New York State Hospitals*.<sup>52</sup> The authors found that “hospitals with high-performing patient and family advisory councils (PFAC) had significantly higher Hospital Consumer Assessment of Healthcare Providers and Systems scores in terms of patients’ likelihood to recommend, although lower-performing PFACs also performed better than hospitals with no PFAC (high-performing=87 per cent,

lower-performing=86.3 per cent, No PFAC=83.5 per cent,  $p<.05$ ). With regard to performance on Centers for Medicare & Medicaid Services (CMS) quality and safety metrics, hospitals with high-performing PFACs had lower rates of pressure ulcers ( $p<.05$ ), sepsis and septic shock ( $p<.01$ ), and 30-day hospital-wide readmissions ( $p<.01$ ) than hospitals with lower-performing PFACs. However, hospitals with a PFAC, regardless of whether it was high- or lower-performing, performed better than hospitals without a PFAC.”

## 3.3 Partnering in incident management

This section focuses on the opportunities for patient engagement in patient safety incident reporting, incident analysis, and quality improvement processes.

### Reporting

There is emerging evidence that patients can recognize patient safety risks and incidents, some of which are not otherwise identified by existing monitoring systems. They are also willing and able to report this information reliably.<sup>130</sup> It enables healthcare organizations to detect systemic problems in care<sup>131</sup> and identify priorities for safety and quality improvements.

Patients and families are partnering to identify safety risks and concerns in different ways, such as:

- [Saskatchewan’s Stop-the-Line](#), where patients and providers can alert of a safety risk or incident in real-time
- The Canadian Institute for Healthcare Improvement’s [National System for Reporting Medication Incidents](#)
- Complaints reporting systems unique to each healthcare organizations
- Real time reporting of concerns and experiences (see the three [leading practices](#) here)

A patient safety incident management system is developed, reviewed, and updated with input from clients, families, and team members, and includes processes to report, analyze, recommend actions, and monitor improvements.

Leadership 15.4.1



Patient safety incident reporting is still an emerging area for patient engagement.<sup>131</sup> Most incident reporting systems are not set up to include or are not accessible to patients so they can report (e.g., a hard-to-access technical database). Some incident reporting systems are set up specifically for patients. One hospital in the U.S. asked patients to give feedback about the same patient safety incidents as providers reported; the additional information from patients helped identify preventive solutions to build safer care.<sup>132</sup>

Patient partners can work with providers to design and test new methods that engage patients and family in incident reporting. Schneider recently tested a new system-level approach that allows patients and families to report observed safety risks and concerns, patient safety incidents, and near misses online or over a toll-free phone number to a real person.<sup>131</sup> Patient partners helped design the system by providing feedback on the incident reporting forms through focus groups and individual interviews, and testing the final form.

### Incident analysis

“The first thing said and something I will never forget is that the purpose of [the incident analysis] was not to see how the person may have failed the system but how did the system failed the person. That philosophy stuck with me and it was so inspiring and encouraging. The beauty of the [analysis] is that it is very structured and it’s said over and over again that we are not looking at the individual *person*, *we are looking at* what failed in the system.”<sup>133</sup>

- “In the last 12 months, Seattle Children’s Hospital has shifted its expectation from asking ‘Should we involve a parent in this serious safety event?’ to ‘Why wouldn’t we involve a parent in this serious safety event?’ This has presented a major culture shift at Seattle Children’s with providers, leaders, and families. ... We did get initially, and sometimes still, some push back about involving [patient family

advisors] at the table. The feedback we get is that it's just one [patient family advisor]... but sometimes it's just one doctor or one nurse. Having a [patient family advisor] at the table is just like having any other discipline at the table... it is a [patient or family member] who is well-informed, supported and educated about how to be at that table.”<sup>133</sup>

Incident analysis is part of responding to a patient safety incident that resulted or could have resulted in harm. Other terms used for harmful patient safety incidents include “critical incident” and “adverse event.” Incident analysis<sup>66,134,135</sup> is a structured, objective process that aims to determine:

- What happened?
- How and why it happened?
- What can be done to reduce the likelihood of recurrence and make care safer?
- What was learned?

The process:

- Is guided by thorough information gathered about the incident and best practices for the care processes related to the incident
- Focuses on understanding what went wrong in the system (system failure) rather than on placing blame on an individual involved in the incident
- Helps with understanding the whole care system that contributed to the incident, and the human factors (e.g., peoples’ behaviours, abilities, limitations, and their relationship to the physical organization and cultural work environment). Understanding human factors helps improve technology design, processes, and work systems to be safer, efficient, and effective.
- Results in recommended actions to strengthen safety of systems and care processes, which may result in specific safety improvement initiatives

Because harmful incidents may have serious consequences for the patient and family, the review process can be emotional. Take care to provide practical and emotional support to patients, families, and healthcare providers as well as those reviewing the case and recommending a plan to prevent future harm.

## **How are patients and family engaged in incident analysis?**

After a patient safety incident occurs, gather initial information to determine the actions that should be taken to understand what happened and to develop recommendations to prevent a future similar incident.

For an incident where a patient has experienced serious harm, conduct a formal incident analysis process that involves a review team. The specific method used to analyze the incident, and patient and family involvement, varies among healthcare organizations.

The patient and family directly affected by the incident should receive information through the disclosure process, an incident analysis interview, and through updates about follow-up actions. They may also choose to be more involved in organizational change for their own healing journey.

Etchegaray et al.<sup>136</sup> found that patients and families are somewhat aware about what contributed to their incident. Out of 72 people interviewed, all could identify at least one factor that contributed to the incident and, on average, people identified three to four factors. The most frequently mentioned factors were:

- Provider qualifications/knowledge (79 per cent)
- Safety policies/procedures (74 per cent)
- Communication (64 per cent)

Patients and families identified these factors from their own personal observations (32 per cent personal reasoning (11 per cent), personal research (7 per cent), record review (either their own medical records or reports they received in their own investigation) (6 per cent), and being told by a physician (5 per cent). They were also able to provide suggested actions to address each of the contributing factors. Most people in the study were not involved in the incident analysis process, so vital information may have been missed. The study concluded that healthcare organizations should interview patients and families about the event that harmed them to help ensure a full understanding of the causes of the event.

In Alberta, patients and families are involved in two steps of patient safety incident reviews:<sup>135</sup>

- Interviewed at the information-gathering stage to gain their understanding of the incident's cause, what could have prevented it, and any actions they think the organization should take to improve the safety of the system
- Invited to review draft recommendations for feedback and refinement

Patient partners can be involved in helping the organization learn and improve after patient safety incidents by:

- Bringing the patient voice to an organizational safety and quality committee responsible for policies and processes to monitor and improve safety and quality
- Participating on quality improvement teams that design and test improvements to improve safety of care processes

Involving patient partners in incident analysis is a specialized and emerging practice.<sup>137</sup> It requires training for the patient partner and the team or committee. Patient partners bring a unique and valuable perspective, especially in identifying areas where things went wrong and opportunities to improve.<sup>108</sup>

Incident analysis teams typically have four to six members, including providers with expertise in the related care process and people from different levels of the organization. Do not include people who were directly involved in the incident but interview them for information—both patients and their families, and providers.

Organizations should gain experience engaging patient partners in other ways before bringing them into a complex, sensitive process, such as incident analysis. Demonstrating positive results from other patient engagements will help create a supportive culture with the trust needed to bring a patient partner to the incident review table.

Select the patient partner and prepare, train, and support them to participate on the incident review team. As with any member of the review team, the patient partner should sign a confidentiality agreement and keep sensitive information private. Overcome challenges with sending confidential information over e-mail by communicating verbally with the patient partner before meetings and providing them with written information to review on-site before and during meetings.

The Healthcare Safety Investigation Branch<sup>138</sup> in UK is engaging patients, families and carers in their independent

investigations. On their public [website](#) they provide clear description of the investigation process and guide patients to find support.

## Developing a strong analysis team

Incident analysis involves very confidential, sensitive, and often legally protected information. It is an emotionally charged situation, where feelings of shame, embarrassment, and fear can risk harming the participants. For these reasons, building trust is imperative. Strategies include:

- Providing opportunities for providers and the patient partner to talk to each other about their hopes and concerns about participating on the team
- Being clear that the organization has a just culture and that incident review is focused on understanding “how the system failed the person, not how the person failed the system.” A just culture balances two factors: understanding system failure, and the responsibility and accountability of providers delivering care.
- Approaching patient engagement in analysis incrementally:
  - Decide how you will measure success of the partnership in incident analysis
  - Begin with one experienced patient partner who is well trained, well informed, and well supported to participate
  - Start with a simpler incident review
  - Test out the process
  - Review together and assess success. What worked well and what could be improved?
  - Build on success slowly, training a small number of experienced patient partners to participate to build relationships and ensure consistency
  - Support experienced patient partners to mentor newer patient partners
  - Create opportunities for patient partners to come together to support each other and share learnings

<b>Concerns of staff/providers about involving a parent in incident analysis<sup>133</sup></b>	
<b>Concerns from providers</b>	<b>Response from patient partners</b>
<p>What if the patient or family member (e.g., child) is still receiving care in the area being discussed? Won't that destroy the trust they have in the organization or service?</p> <p>What if it hits too close to home for the patient partner? We don't want to make things harder for them.</p> <p>What if they feel scared it could happen to them or their family member?</p>	<ul style="list-style-type: none"> <li>• “Makes me feel more secure and trusting because it takes a lot to admit fault.”</li> <li>• “Builds more trust because things you would think the hospital doesn't notice... you see that they do notice them.”</li> <li>• “A lot of patients and families don't realize how much respect the provider has for them.”</li> <li>• “I trust them more, ten-fold.”</li> <li>• “I now feel less intimidated when I come in for her care.”</li> <li>• “It didn't change my trust because what came to the forefront was the dedication of everyone in the room to face the hard issues... to find out why this happened and not just try to grasp something simple or easy to fix and hold it up as the cause.”</li> </ul>

Experienced patient partners and providers will more likely have the skills needed to participate in a patient safety incident analysis because they:

- Are confident speaking up in groups that include figures of authority (e.g., leader, director of a clinical area)
- Have insight into their own emotional triggers and the emotional responses of others (e.g., discussing the details of an incident of harm can be distressing to all involved)
- Are comfortable with technical discussions

While it is useful for the patient partner to have had some personal experience with the procedures/diagnoses for the incident, don't involve someone "too close to home." Have an open conversation with the potential patient partner about the risks and benefits to arrive at the best decision.

Orient patient partners to a patient safety incident analysis team:

- Ensure experienced patient partners are well-briefed and well-prepared before the first review meeting
- Share the following information in advance:
  - The method for the incident analysis
  - Common and likely patient safety and medical terms
  - Analysis scope, including any concepts or best practices that may help understand what led to the incident and what actions could be taken to prevent a future similar incident
  - Areas where the patient or family perspective is most needed
  - Potentially contentious discussions areas and conflicting opinions
- Debrief the patient partner after participation to provide emotional support, appreciate their work, and learn how to improve the process
- Debrief the incident review team with a follow-up survey to the team leader or through a follow-up discussion with the team leader or full team (see the following table for possible questions)

<b>Kalbach et al. recommend the following debrief questions after incident analysis<sup>133</sup></b>	
<b>Patient family advisor</b>	<b>Incident analysis team (lead or full team)</b>
<ul style="list-style-type: none"> <li>• What was it like for you to be involved?</li> <li>• How did you feel about your contribution?</li> <li>• Do you have questions or are you confused about anything you heard?</li> <li>• Were details discussed that were difficult for you to hear/process? (emotional impact of involvement)</li> </ul>	<ul style="list-style-type: none"> <li>• How did the patient partner's participation impact the outcome?</li> <li>• Are there ways we can better prepare patient partners for involvement?</li> <li>• Are there ways we can better prepare staff/ providers for involving a patient partner?</li> </ul>

## Learning from patient engagement at the organizational level

Partnership requires regular check-ins to assess what is working well and what needs to be improved. Sometimes obvious tension points need to be addressed to prevent them from getting in the way of the improvement work. As a safety or quality plan or project wraps up, set aside time to evaluate the experience of working together. Do this through dialogue, exit interviews, or structured feedback surveys. Use lessons learned from the evaluation to strengthen partnerships in the future.

### Questions to assess the patient partner engagement in improvement<sup>93</sup>

- How at ease did you feel by joining the team?
  - What was your experience of welcome by the team (respect, language, fairness, and understanding)?
  - Have you felt like a full member of the team?
  - Were you comfortable communicating your ideas and perspectives?
  - To what extent did you feel that your ideas and perspectives were considered by other team members?
- What most helped your participation in the team?
  - Did you receive support from anyone to help you participate (e.g., staff person, coach, experience patient partner)? How did they help?
  - What other support would have been helpful?
- What do you most appreciate about your contribution?
- To what extent did the objectives of the initiative address the needs of patients and family? What do you think are the greatest impacts that the work may have on patients and family?
- In your opinion, what did you bring to the team/to the improvement process?
- How did you personally benefit from participating? What skills did you gain?
- How did your participation benefit the organization?
- What is your overall satisfaction with your involvement on the team?
- What are the greatest challenges/obstacles to involving patient partners in these quality improvement processes?

## 3.4 Summary - what you can do



### Patients, families, and patient partners

- Find out how to participate in quality and patient safety work.
- Reflect and be honest about your motivations for becoming a patient and family partner.
- Learn how to become an effective patient partner; ask for and access available support.
- Get clarity about your role, expectations, and the purpose of the work.
- Ask about or suggest ways to bring in more patient perspectives when needed.
- Learn about the organization's quality and safety frameworks, tools, and training.
- Find out when and how you will hear about project outcomes and next steps.
- Understand the patient engagement processes and help identify gaps and solutions.
- Ask how to get involved in incident analysis and incident management.
- Find out the procedure and resources available to patients and families after harm.
- Share your questions, concerns, and improvement ideas to the incident management process.



### Providers, patient engagement specialists

- Understand how patient engagement in patient safety is organized and resourced.
- Reflect on your beliefs, attitudes, and behaviours about patient engagement.
- Improve your patient engagement competencies and skills with feedback from patient partners.
- Learn about, champion, and help advance authentic patient engagement best practices.
- Support patient partners and team or committee members engage effectively:
  - Facilitate a good fit between patient partners and the work.
  - Ensure everyone has relevant information to effectively participate.
  - Involve patient partners as early as possible and establish lines of communications.
  - Create rules of engagement early on to set shared principles and mutual expectations.
  - Create a safe space for all—especially patient partners—to speak up.
  - Check in with everyone regularly to see how engagement is going and what to improve
- Follow your organization's patient engagement in patient safety incident management policies.
- Ensure all involved, including you, have access to support after an incident.



### Leaders

- Support patient engagement in your organization:
  - Embed expectations for working with patients and families as partners.
  - Provide an organizational framework, training, and support for patient engagement.
  - Position patient engagement structures and functions to effectively influence and contribute to patient safety, organizational goals, and priorities.
  - Communicate about patient engagement internally and externally.
- Nurture, support, and sustain patient engagement in patient safety:
  - Integrate patient engagement with patient safety across the organization, clarifying how teams, departments, and programs influence one another.
  - Ensure time and resources for patient engagement are appropriately allocated.
  - Provide opportunities for staff, patients, and families to learn how to create safe care.
  - Ensure a collaborative process for developing safety and quality improvement plans.
  - Test and embed promising patient engagement practices in your organization.
- Incident management:
  - Value the role that patient partners play in responding to patient safety incidents.

## 3.5 Practice examples

### Patient engagement in incident analysis - Seattle Children's Hospital

Seattle Children's Hospital uses root cause analysis (RCA) as the method to understand what happened after a serious patient safety incident and to develop recommendations for action. A multidisciplinary team includes anywhere from five to 20 people, depending on the type of incident, but not the individuals who were part of the event (e.g., the physician, nurse, other care providers). Roles of those supporting the review team are described in the following table.

It has been a challenge involving patient family advisors in reviewing serious incidents, and the organization continues to learn from and build upon their experience. Extensive work has been done to create a dialogue between patients, families, and staff involved in incident review to understand the barriers to involving patients and families, and to build trust and mutual understanding. This has shifted the way that root cause analysis is done in the hospital.

Currently, the organization has a policy that an experienced patient family advisor (PFA) is involved as a member of every RCA.

- To date, five PFAs have been trained to take on this role to provide consistency and to learn how to refine and strengthen their engagement in the process.
- A recent survey found that 60 per cent of PFAs in the organization were interested in participating.

Seattle Children's Hospital review of serious patient safety incidents	
Roles	Responsibilities
Facilitator(s) of the RCA  Staff of quality and safety team/ department	<ul style="list-style-type: none"> <li>• Conduct interviews with each person involved in the incident (patient, family, healthcare providers) before the review team comes together</li> <li>• May observe care processes, research on best practices, document-related policies and procedures</li> <li>• Lay out the timeline, the context, and each person's description of what happened and why</li> <li>• Prepare structured tools to help the team (e.g., a care process map, a cause and effect diagram).</li> </ul>
Health leader	<ul style="list-style-type: none"> <li>• Make sure the RCA team is supported</li> <li>• Understand the challenges surrounding the incident</li> <li>• Remove barriers that could block the process or the action items</li> </ul>
Process owner: Director of the clinical area or whoever has oversight of where the incident occurred	<ul style="list-style-type: none"> <li>• Help coordinate the investigation</li> <li>• Present the information at the review team meetings</li> <li>• Assist in completing the action items</li> </ul>
Team members: provider and experienced patient partner	<p>Those who can speak to similar events or experience in the care processes:</p> <ul style="list-style-type: none"> <li>• Review the case</li> <li>• Help determine the causes</li> <li>• May be responsible for owning action items.</li> </ul>
Patient engagement specialist	<ul style="list-style-type: none"> <li>• Help to recruit and select the experienced PFA to participate on the team</li> <li>• Work with the quality and safety team to train and prepare the PFA</li> <li>• Provide support before, during, and after the review</li> </ul>



## 4. Evaluating patient engagement

“I’m always suspicious of a measurement approach that doesn’t involve any opportunity for discussion with the respondent... there are some situations that just cannot be addressed by any survey – to hear about them, we just have to talk to people. It’s all about connection – that’s what’s been lost and that’s what needs to be restored.”<sup>139</sup>

Methods to evaluate engagement processes and their impact are quite new in healthcare. Evaluating patient engagement efforts provides patients and families, healthcare providers, and organizations with information to recognize successes, identify improvements, and validate patient engagement as an input to decision-making. It also:

- Helps everyone involved reflect and learn from their engagement experience to make improvements, whether at the point-of-care or in organizational processes and planning
- Provides public accountability by ensuring that what is measured and reported matters to patients
- Builds evidence for patient care, engagement practices, and care outcomes that help shift individual behaviours and organizational processes. This supports investing in the people and structures needed for effective and purposeful engagement.
- Evaluating patient engagement should include everyone’s perspectives. Evaluation can take place at all levels in a healthcare organization and occurs at all stages of an initiative from planning to final analysis. This chapter covers the critical steps in planning for evaluation and provides measures and tools that can evaluate patient engagement at the point-of-care and organizational level, to help integrate patient engagement into the organization.

## 4.1 Introduction to evaluation

Patient engagement in the healthcare system is a relatively new development, though it is becoming more common. Methods to evaluate engagement processes and their impact are also quite new.<sup>39,58,140</sup>

Evaluation involves systematically assessing an initiative’s design, implementation, and results to learn or influence decisions.<sup>141</sup> It requires collecting and analyzing information about the program’s activities, characteristics, and outcomes. Collecting this information involves using predetermined measures, also called indicators in evaluation literature.

Patients and families participate on evaluation teams, committees, and improvement teams, to help develop surveys and other methods to evaluate their experiences. They are involved in all stages, supporting planning, developing tools, collecting information, and analyzing data. Patient experiences about the quality, safety and timeliness of the care they received can be gathered through ‘real time’ for quality and safety improvement initiatives.

At the most basic level, evaluation is trying to answer questions about:

- **Process:** How were patients and families engaged? What worked well? What needs to be improved? Was the engagement meaningful?
- **Outcomes:** What were the results of the engagement (e.g., tools, strategies, learning programs, policies)? Did clinical practices improve?
- **Impact:** How did engaging patients and families affect their care experience? What was the impact of patient engagement on safety and quality of care and health outcomes? Did it contribute to positive change?

Evaluation often starts by measuring process and making improvements to the initiative or activity. Over time, it is better able to assess outcomes and impacts.

### Examples of evaluation measures (adapted from Alberta Health Services)

Engagement process measures	Engagement outcome measures
<ul style="list-style-type: none"> <li>• Patient, family, and healthcare provider readiness to partner with each other</li> <li>• Representativeness (i.e., those participating in the evaluation are typically those involved in the program)</li> <li>• Diversity of views, opinions, and lived experiences.</li> <li>• Early involvement</li> <li>• Clearly defined task(s), roles, and responsibilities</li> <li>• Decision-making process transparency</li> <li>• Patient, family, and healthcare provider satisfaction</li> <li>• Timeliness, participation rate, and costs</li> <li>• Effects of context and changing environment</li> </ul>	<ul style="list-style-type: none"> <li>• Influence on setting priorities and decisions</li> <li>• How well patients and families were heard and understood</li> <li>• Effect on attitude of patients and families and healthcare providers towards engagement</li> <li>• Overall engagement experience satisfaction</li> <li>• Engagement goal and promises met</li> <li>• What patients, families, and healthcare providers learned from each other</li> <li>• Effect on relationships, team effectiveness, and trust</li> <li>• Effects on context and changing environment</li> <li>• Unintended (positive and negative) consequences</li> <li>• Practice and clinical improvements (e.g., improved medication adherence, decreased hospital-acquired infections)</li> </ul>

Context can be assessed from both a process and an outcome perspective. To illustrate, a significant patient safety incident that occurs midway through a process evaluating patient safety could affect both the evaluation and the outcomes. Assessing the social, cultural, and/or policy context, including predominant views towards patient engagement, may be important in understanding varying results across units or facilities. Differences in organizational arrangements (e.g., patient access to electronic health records, or whether families are considered “visitors”) may also be important.

It can be challenging to attribute outcome and impact changes entirely too patient engagement. There may be multiple initiatives going on that influence impacts, or the impact of engagement may be an intermediate step in achieving those outcomes. For example, partnering with patients on the care team or in a co-design process can generate possible solutions. These solutions then need to be implemented and tested and may lead to better results.

There are different interpretations about what is important to evaluate. Often both [quantitative and qualitative measures](#) are included.

Quantitative measures, that focus on things that can be counted (e.g., number of participants, on a scale of one to five, how satisfied are you with the hospital food?) tend to be more common. However, qualitative measures, that capture accounts of experiences, descriptions, observed behaviours (e.g., patient and health provider stories and experiences) are also important. Many patients and families want to provide fulsome and nuanced input (often through conversation), which most quantitative tools, such as surveys cannot accommodate. Both types are important. Numbers facilitate comparisons. Qualitative data offers detail and nuance, capturing contextual factors and variation.<sup>142</sup>

More work is needed to develop and share practical tools for measuring engagement process quality and its impact on healthcare processes and health outcomes.<sup>139,143</sup> Partnering patients and families with those responsible for monitoring and measuring patient- and family-centred care and patient engagement will make the information more meaningful and understandable.

## Planning for evaluation

Considering evaluation at the earliest stage in planning helps clearly define an initiative’s objectives and offers a shared understanding of success and how it will be assessed. This also ensures that evaluation data is collected throughout the process. An evaluation plan should be developed with patient partners as part of the project team whenever possible.

Include the following components in an evaluation plan:<sup>144</sup>

Components	Description	Examples
Purpose	<ul style="list-style-type: none"> <li>Why are you conducting the evaluation and how will the results be used?</li> </ul>	<ul style="list-style-type: none"> <li>Judge program merit or worth</li> <li>Improve programs</li> <li>Generate knowledge</li> <li>Increase engagement, motivation, and ownership</li> </ul>

Components	Description	Examples
		<ul style="list-style-type: none"> <li>• Accreditation</li> </ul>
Target audience(s)	<ul style="list-style-type: none"> <li>• Who are the intended recipients or users of the evaluation results?</li> </ul>	<ul style="list-style-type: none"> <li>• Patient partners</li> <li>• Healthcare providers</li> <li>• Board of directors</li> </ul>
Participants	<ul style="list-style-type: none"> <li>• From whom will the data be collected?</li> <li>• Who will conduct the evaluation?</li> <li>• What preparation is needed for people to best fulfill their roles?</li> </ul>	<ul style="list-style-type: none"> <li>• Frequent users</li> <li>• Frontline providers, patient, and family partners</li> <li>• External evaluator</li> </ul>
Evaluation questions and measures	<ul style="list-style-type: none"> <li>• What questions will be asked?</li> <li>• What needs to be measured? How?</li> <li>• How will data be collected?</li> <li>• Use a logic model/theory of change/driver diagram to frame the questions<sup>145</sup></li> <li>• Consider ethical or privacy issues</li> </ul>	<ul style="list-style-type: none"> <li>• Did patients and families feel their perspectives were heard?</li> <li>• What was their experience?</li> </ul>
Methods and tools	<ul style="list-style-type: none"> <li>• What is the best approach to get the data?</li> <li>• What tools will help collect this data and what training may be required to use the tool?</li> </ul>	<ul style="list-style-type: none"> <li>• Surveys, interviews</li> <li>• Interview script, survey tool</li> </ul>
Data collection strategy	<ul style="list-style-type: none"> <li>• What data needs to be collected?</li> <li>• When will it be collected and by whom?</li> </ul>	<ul style="list-style-type: none"> <li>• Observational data</li> <li>• Patient narratives</li> </ul>
Analysis	<ul style="list-style-type: none"> <li>• How will the data be analyzed?</li> <li>• Is the amount of data to be collected manageable (i.e., only what can be used)?</li> </ul>	<ul style="list-style-type: none"> <li>• Text analytics</li> <li>• Thematic content analysis</li> <li>• Statistical analysis</li> </ul>
Result communications	<ul style="list-style-type: none"> <li>• Who is the target audience?</li> <li>• How can results best be shared with the target audiences?</li> </ul>	<ul style="list-style-type: none"> <li>• Written report, infographic</li> <li>• Presentation, workshop</li> </ul>
Required resources	<ul style="list-style-type: none"> <li>• Determine and secure the resources needed for the evaluation</li> <li>• This will also help verify the extent of the evaluation</li> </ul>	<ul style="list-style-type: none"> <li>• Time</li> <li>• Money</li> <li>• Expertise</li> <li>• Number of measures.</li> </ul>

## Methods and tools for evaluating patient engagement

Many evaluation methods and tools exist, and some have been adapted for use in healthcare. Consider using validated tools where possible. These tools have been rigorously tested, and help ensure data collection consistency (e.g., if there are multiple evaluators). These tools also allow organizations to compare data and results across different projects, within the same or across different organizations.

Examples of tools include:

- The [Public and Patient Engagement Evaluation Tool \(PPEET\)](#), which measures the quality and impact of engagement, and is currently being tested.<sup>146</sup> It may be used in a variety of healthcare organizations.<sup>39</sup> Using [three questionnaires](#), it measures four key elements of quality engagement:
  - Integrity of design and process
  - Influence and impact

- Participatory culture
- Collaboration and common purpose
- The three questionnaires target those who:
  - Participate in patient and public engagement activities (e.g., patients, public)
  - Plan and execute activities within organizations (e.g., patient engagement specialists)
  - Create the vision and build capacity for engagement within their organization (e.g., leaders)

The [Patient and Public Engagement Evaluation Toolkit](#)<sup>148</sup> is a resource designed for practitioners of the health sector, produced after the completion of a rigorous systematic review of patient and public engagement evaluation tools. The searchable database includes a wide range of tools to assist in the evaluation of patient and public engagement initiatives, both in health research and in healthcare.

Additional examples of evaluation tools and resources are available [online](#).



## 4.2 Evaluating patient engagement at the point of care

Throughout this guide, two broad areas of patient engagement are considered, requiring different approaches for measurement and evaluation:

- **Point-of-care engagement:** How patients and families engage in their own care
- **Organizational and unit-level engagement:** Patient partners in committees, working groups, or processes aimed at improving quality and safety

Prepare patients and families for evaluation at the point of care so they understand why the data is collected, by whom, and how the findings will be used. Usually this information (and more) is included in the data collection tool but providing an opportunity to ask questions is usually helpful.

### Measures and tools for evaluating patient engagement at the point of care

Much of the work to date developing point-of-care measures and tools originates from monitoring and evaluating how patient and family-centred care (PFCC) is being implemented in healthcare organizations.<sup>149</sup>

The American Institute for Research has developed an inventory of patient engagement measures, many of which are linked to PFCC.<sup>150</sup> The database presents different measurement areas and the tools used to gather information. Some measurement examples for point of care are included in the following table. Health Standards Organization's standards for client and family-centered care align closely with these broad measurement areas. Two examples are provided in the table and textbox below.

Excerpt – patient engagement measures inventory			
Measurement area	Measurement examples	Measurement tool examples	Completed by
Access to medical records	 There are policies and processes to allow clients to easily access the information in their health record in a routine and timely way. <a href="#">Leadership 11.4</a>	PFCC Organizational Self-Assessment Tool <sup>151</sup>	Providers, although some questions could be adapted for patients to complete
Care processes	 Conduct shift change report at the patient's bedside Clients and families are actively engaged in planning and preparing for transitions in care. <a href="#">Mental Health Services 7.1</a>	Patient-Centered Care Improvement Guide Self-Assessment Tool <sup>152</sup>	Providers, although some questions could be adapted for patients to complete
Care transitions	 Planning for care transitions, including end of service, are identified in the care plan in partnership with the client and family. <a href="#">Public Health Services 3.12</a>	IPFCC Hospital Self-Assessment Inventory <sup>153</sup>	Providers

Excerpt – patient engagement measures inventory			
Measurement area	Measurement examples	Measurement tool examples	Completed by
Communications	Each client's preferences and options for services are discussed as part of the assessment, in partnership with the client and family. <a href="#">Ambulatory Care Services 3.7</a>	Patient-Centered Care Improvement Guide Self-Assessment Tool <sup>152</sup>	Providers, although some questions could be adapted for patients to complete
Leadership support	 Resource allocation is a part of the regular planning cycle for the organization. <a href="#">Leadership 8.1</a>  Teams are supported in their efforts to partner with clients and families in all aspects of their care. <a href="#">Leadership 1.4</a>	Checklist to Improve Effective Communication, Cultural Competence, and PFCC <sup>154</sup>	Providers
Shared care planning and decision-making	 Clients and families are encouraged to be actively engaged in their care. <a href="#">Cancer Care 9.3</a>	CollaboRATE <sup>155</sup>	Patients/families

Clients are able to access information in their records, including electronic medical/health records, in a routine, client-centred, and timely way.<sup>1</sup> Planning for care transitions, including end of service, are identified in the care plan in partnership with the client and family.<sup>2</sup>

<sup>1</sup> Correctional Services of Canada Health Services 14.4

<sup>2</sup> Critical Care Services 4.16



Surveys are a primary source of quantitative data and highlight key improvement areas. While they can tell you *what* people think and experience, they do not necessarily tell you *why*. It is usually not possible to ask follow-up questions to better understand a patient's responses. Using a mix of measures (both quantitative and qualitative) and tools provides for more robust evaluation findings. [Measuring patient experiences through surveys: from concepts to best practices](#), developed by Institut de la Statistique du Québec, for instance, provides an outline of good survey practices that could upgrade the use of the information gathered from patients for both quality improvement and performance evaluation purposes.

Qualitative data, to better understand patient engagement experience nuances, is collected in different ways. Patients (and/or PFAs and volunteers) sometimes play an active role in collecting this data. Collection methods include:

- One-on-one interviews (e.g., Patient Family Voices Volunteers interview and document patient and family perceptions of their hospital care experience)<sup>62</sup>
- Focus group discussions (e.g., Small groups gather to discuss and explore their views in detail, providing an opportunity to listen to a range of opinions and experiences)
- Direct patient engagement observations at the point of care, sometimes using video<sup>10</sup>

- Ipads or postcards to gather feedback on key questions, such as:<sup>156</sup>
  - Please share one positive example from your recent office visit/hospital experience
  - Please share one example that could have been improved
  - If you could make one change in the care you received, what would it be?

For over a decade the Organization for Economic Cooperation and Development (OECD) has supported patient safety efforts leading efforts to develop and establish internationally comparable patient safety indicators.<sup>157</sup> The 2019 [Patient-Reported Safety Indicators: Question Set and Data Collection Guidance \(PRIMs\)](#) describes the process and questions being pilot tested which inform indicator development.

## Using patient experiences data to evaluate engagement at the point of care

Patient and family experience data contributes valuable information for patient engagement evaluation in patient safety. Formal and informal monitoring systems collect patient and family experience data and bring the information into planning and evaluation processes. One of the most common tools is the survey.

Several Canadian organizations have included questions related to patient safety in their patient experience survey.

The Canadian Institute of Health Information is currently testing out a new patient experience survey that includes [Consumer Assessment of Healthcare Providers and Systems](#) measures plus additional Canadian measures.<sup>158</sup> Organizations that use these standard surveys can share their data and compare with other organizations or health regions. A national system is in place to share, analyze, and use this patient experience data to identify areas for improvement in the health system.<sup>159</sup> Here are some examples of patient experience survey measures from the Canadian Patient Experience Hospital Inpatient Survey:

- During this hospital stay, how often did nurses (doctors) listen carefully to you?
- During this hospital stay, how often did nurses (doctors) explain things in a way you could understand?
- Did you get the support you needed to help you with any anxieties, fears, or worries you had during this hospital stay?
- Were you involved as much as you wanted to be in decisions about your care and treatment?
- Was your family (or friends) involved as much as you wanted in decisions about your care and treatment?

The Institute for Patient and Family-Centered Care in the United States has developed one-page key measure dashboards for patient and family-centered care (hospital or outpatient clinic).<sup>104</sup> The dashboards show results from select standard survey questions and tools that measure how well the organization is advancing patient and family-centered care. Key patient safety and quality measures are also included (e.g., rates of incidents, hospital readmission rates, emergency department admission rates). Other key measures are listed as a “yes/no” checklist:<sup>103</sup>

- Discharge planning checklist
- Shift huddles and bedside shift report
- An accountable leader for patient engagement
- Patient engagement committee or patient partners on committees
- One or more patient representatives serving on the board of directors

Primary care providers can measure their patients’ experiences in their practices with the Primary Care Patient Experience Survey. The survey was developed by Health Quality Ontario in collaboration with the Association of Family Health Teams of Ontario, the Association of Ontario Health Centres, the Ontario College of Family Physicians, and the Ontario Medical Association.<sup>160</sup>

Regular processes for partnering with patients and families to monitor and evaluate quality and safety can be enhanced if they consider patient experience data and other measures of patient engagement.

The Health Research and Education Trust<sup>161</sup> developed a [Leadership Resource for Patient and Family Engagement Strategies](#), which describes practical examples of patient engagement linked to measures and outcomes. While largely quantitative measures are provided as examples, the following table (adapted) provides a good link between engagement, measures, and outcomes or improvements.

Description/process	Measurement	Outcomes
Patients and families participate in rounds; orders and discharge paperwork are clarified; patients and families are involved in decisions	<ul style="list-style-type: none"> <li>• Percentage of patients and families that participate in rounds</li> <li>• Number of stories in which new information is discovered from patient and family</li> <li>• Length of time for rounds</li> <li>• Patient and family satisfaction scores</li> <li>• Staff satisfaction scores</li> <li>• Length of stay</li> </ul>	<ul style="list-style-type: none"> <li>• Decrease in length of stay</li> <li>• Increase in satisfaction scores</li> <li>• Decrease in readmissions rate, safety outcomes</li> <li>• Change in percentage of near misses versus harmful incidents</li> </ul>

## 4.3 Evaluating patient engagement at the organizational level

It is also important to measure patient engagement quality and impact at the organization and system levels. This includes patient and family advisory councils, patient and family committees, and working groups or teams at various organization levels serving different purposes (e.g., service design, policymaking, quality improvement, and safety).

Patients and families are also engaging as partners in the evaluation process to help identify appropriate measures, develop, and implement measure tools, analyze findings, etc. Remember to prepare patients and families to co-design and support evaluation. For example, Patients for Patient Safety Canada volunteers selected for evaluation committees are oriented by staff to the specific task and to the team. Evaluations they contribute to include: advisors to the [independent evaluation of Patients for Patient Safety Canada](#), leads in the post-participation evaluation of [Patients for Patient Safety Canada](#), members of the Evaluation Action Team mandated to evaluate the [National Patient Safety Consortium and the Integrated Patient Safety Action Plan](#).

## Measures and tools for evaluating patient engagement at the organizational level

Patient engagement evaluation at this level can easily draw from the broader field of public engagement, which includes but is not specific to patient engagement.

Quantitative measures often track what is being done, including the number of patients and families engaged, the number and type of activities where patients or family were engaged, or the number of requests for patient partners.

To understand if the engagement was meaningful to participants, evaluate if engagement process goals were achieved, and track and understand engagement quality. Achieving meaningful engagement requires that participants:

- Know the purpose for their involvement
- Have good and comprehensive information to support their participation
- Can freely voice their ideas and concerns
- Know what will happen with their input
- Have evidence of the commitment of decision-makers to respect their input
- Are informed about the decisions made, and how their involvement informed these decisions

In the PPEET,<sup>146</sup> engagement quality is assessed (at least in part) through the “integrity of design and process,” which includes these outcomes:<sup>39</sup>

- Public and Patient Engagement (PPE) participants represent the diverse range of views of those most affected by the decision
- Participants have access to supports that enable participation, such as:
  - Meeting-related expenses
  - Compensation, where possible
  - Comfortable, non-threatening, and convenient activity locations, amenities, times, and days
  - Relevant information, produced at an appropriate education level
- Clear, two-way communication exists between organizers and participants:
  - Process and objectives are clearly communicated
  - Participants understand how their input will be used
  - The outputs of the PPE activity process are reported to participants, including how their input will be used in the decision

These are evaluated through the participant and project questionnaires. Respondents use a five-point scale to rate measures, such as:

- Participant questionnaire:
  - I had enough information to contribute to the topic being discussed
  - I was able to express my views freely
  - I think this activity will make a difference
- Project questionnaire:
  - The project plan had a clear strategy to identify and recruit those most affected by the decision
  - The project plan included a clear statement about how goals and expectations for the PPE activity would be shared with participants
  - The project plan indicated how PPE input would be used

More organizations are measuring not just how many people are involved, but also who is involved. Collecting information such as age, language, and cultural background helps monitor perspective diversity and sets targets for more equitable engagement. This includes engaging those who are more vulnerable and marginalized or where there might be barriers to their engagement (e.g., language).

The American Institute for Research has developed an inventory of patient engagement measures.<sup>150</sup> The database presents different measurement tools to gather information. Some measurement examples for the organizational level are included in the following table.

Excerpt – patient engagement measures inventory			
Measurement area	Measure example	Measurement tool examples	Completed by
Leadership support	 Teams, clients, and families are supported to develop the knowledge and skills necessary to be involved in quality improvement activities. <a href="#">Leadership 3.3</a>  Leaders provide resources (in the form of time, money, personnel) to support patient engagement	Checklist to Improve Effective Communication, Cultural Competence, and PFCC <sup>162</sup>	Providers
Participation in organizational partnerships	 There are clear, documented processes shared with clients and families about how to file a complaint about the organization or their care, or to report a violation of their rights. <a href="#">Leadership 3.4</a>	Patient Engagement Survey <sup>163</sup>	Senior leaders (e.g., CEO, CNO), although some questions could be adapted for patients to complete
Policies	 There is regular dialogue between the organization's leaders and clients and families to solicit and use client and family perspectives and knowledge on opportunities for improvement. <a href="#">Leadership 3.6</a>  Patient partners help develop, implement, and evaluate a hospital's family presence policy.	Better Together Partnering with Families – Organizational Self-Assessment <sup>164</sup>	Providers
Structures	 Services are co-designed with clients and families, partners, and the community. <a href="#">Service Excellence 1.1</a>  Patients and families participate on committees, workgroups, and/or task forces.	Patient-Centered Care Improvement Guide Self-Assessment Tool <sup>152</sup>	Providers, although some questions could be adapted for patients to complete

A comprehensive orientation is provided to new team members and client and family representatives<sup>1</sup>. Services are co-designed with clients and families, partners, and the community.<sup>2</sup>

<sup>1</sup> Service Excellence 3.3

<sup>2</sup> Service Excellence 1.1



Patient partner engagement at the organizational or unit level often requires ongoing and long-term collaboration. The Evaluate Team Collaboration Skills tool provided in A Resource Toolkit for Engaging Patient and Families at the Planning Table<sup>165</sup> evaluates collaboration quality and how it changes over time. It assesses respect and diversity, structure of participation, and trust on a five-point scale as shown in this trust scale:

Domain	Old ways	First steps	Making headway	Picking up speed	Strong momentum
Trust	I think that others' intents are self-serving. I am afraid to say what I think.	I'm observing and assessing the safety of the group, such as people's attitudes and non-verbal communication, and whether I have peers here.	I'm experiencing dialogue which gives me the opportunity to hear others' views. I don't think the group punishes people who express contrary opinions.	I mostly trust the good intentions and motives of others in the group. I am coming to believe in the value of what we can learn from each other.	I realize that the best resolutions require everyone's contributions and expertise.

Self-assessment tools are also useful. For example, Spectrum Health<sup>166</sup> developed a [goal-setting tool](#) to help patient and family advisory councils (PFACs) reflect on their work during the previous year and set goals for the coming year. Spectrum Health is an integrated health system in the United States, with 17 active PFACs that incorporate patient and family perspectives when planning how care should be provided.

- Using a 10-point rating scale, PFAC members used a self-assessment tool to individually and collectively rank where they felt the PFAC was collaborating effectively (meetings, PFAC members, health leaders engaged with the PFAC, and alignment of PFAC goals with key organizational strategies and service goals).
- The assessment results helped the PFAC plan for improvements and refine their goals for the coming year.

Multifaceted approaches to evaluating patient engagement are also used. A variety of methods and tools were used in the evaluation of the two-year engagement project, Partners Advancing Transitions in Healthcare (PATH):<sup>167</sup>

- These included observational data, surveys, focus groups, interviews, and [patient-reported outcomes using a technology tool](#).
- One method used was [social network analysis](#), which mapped the social networks of all the PATH partners (patients, family caregivers, partner organizations and providers), showing connections and relationships prior to the establishment of PATH (e.g., at the proposal stage) and six months later.
- The results showed how much more interconnected people became over the course of the PATH project, with patients and family caregivers reporting almost 10 times as many connections on average compared to partner organizations and providers.

## 4.4 Evaluating patient engagement integration into an organization

As organizations embed engagement into the way they work, evaluating progress is critical. Keeping it on leadership’s radar is also important. One way to do that is to embed it into existing performance metrics (dashboard or other) or corporate level metrics. For example, the Institute for Patient and Family-Centered Care in the United States has developed [dashboards](#) (one-page graphic summaries) of key measures for patient and family-centered care—for the hospital or outpatient clinic.<sup>104</sup>

- Process measures for engagement of patient and family advisors (PFAs) include number of advisors, hours contributed by PFAs, dollar value of their time, and number and type of committees and teams with PFAs.
- Other key measures of good patient engagement practice are in a “yes/no” checklist:<sup>103</sup>
  - Appointment of an accountable leader for patient engagement
  - Patient engagement committee or PFAs on committees
  - One or more patient representatives serving on the board of directors

The following measures can be used regularly to track patient engagement implementation strategies and organizational impact in hospitals:<sup>161,168</sup>

- The number of advisory councils across the hospital
- Ratio of patient and family members to staff on advisory councils
- Number of patient partners serving on committees or quality improvement (QI) teams
- Number of staff trained in partnering with families
- Number of staff trained in communicating to support patient engagement
- Changes in patients’ ratings of hospital care as patient engagement strategies are implemented
- Changes in clinical process and outcomes as patient engagement strategies are implemented
- Changes in market or financial performance as patient engagement strategies are implemented

These measures point to the importance of organizational culture and the role it plays in engagement processes.

One of the four elements of quality engagement assessed on the public and patient engagement evaluation tool<sup>146</sup> is participatory culture—a significant factor that influences engagement processes.<sup>41</sup> It focuses on these prioritized outcomes:<sup>39</sup>

- The organization promotes and supports ongoing quality public engagement in strategic planning, policy, and service delivery by embedding PPE values and principles in the organization’s philosophy and structure
- Organizational leaders and managers have received training in PPE
- PPE practice is being implemented in service and policy work and is part of standardized business and planning processes

These are evaluated through an organizational questionnaire for senior leaders within the organization (e.g., board members, executive team, department leads, managers, senior project leads and/or project sponsors, and organization partners). Respondents use a five-point to scale to rate measures, such as:

- The organization seeks public and patient input when considering patient safety and quality of care
- A commitment to PPE values and principles is in key organizational documents (e.g., mission and vision, strategy, etc.)
- Comprehensive PPE training and materials are available to support staff
- Organizational leaders ensure that public and patient input is used in service planning and decision-making

**Other dimensions of the organization questionnaire include:**

Policies and practices that support PPE planning and implementation	Influence and impact
<ul style="list-style-type: none"> <li>• An explicit strategy guides the planning of public and patient engagement (PPE) activities</li> <li>• The organization has explicit strategies for identifying and recruiting relevant public and patient participants depending on the engagement activity</li> <li>• There is direct resourcing for PPE within the organization (e.g., through dedicated PPE unit and/or staff)</li> </ul>	<ul style="list-style-type: none"> <li>• PPE reports are sent to relevant predetermined users in the organization (e.g., program manager, senior management, board members)</li> <li>• Organizational leaders or program areas report using input from PPE activities</li> <li>• I am aware of PPE activities that have influenced relevant Board decisions</li> </ul>

Challenges in patient engagement evaluation:<sup>168,169</sup>

- Need for greater specification of both the form and context of engagement
- Need to balance the measurement imperative with the relational aspects of care
- Need for supportive organizations with the capacity and commitment to undertake high-quality engagement and its evaluation

## 4.5 Summary - what you can do



### Patients, families, and patient partners

Ask how to share feedback, experience, and ideas about patient engagement and patient safety by:

- Completing a survey
- Agreeing to be interviewed to share your story
- Participating in a focus group discussion
- Participating in a community meeting or forum to share your experience
- Reading documents

Ask how patient engagement influences patient safety across the organization and/or system by:

- Exploring how decisions will impact patients and families
- Describing what success looks like for patients and families
- Checking if patient experience data is being considered in planning and decision-making
- Suggesting other ways to monitor and evaluate patient engagement
- Asking when and how the learning about engagement activity results will be shared
- Reflecting on your own participation in the process
- Obtaining your engagement results
- Asking if there is an evaluation plan for patient engagement and how to get involved
- Suggesting that the patient and family advisory council assess how it is working together and achieving its goals



### Providers, patient engagement specialists

- Reflect on your own experience with patient engagement and what could be improved
- Regularly review patient experience data to identify improvement opportunities
- Develop an evaluation plan for engagement. Determine which measures can be linked to and inform the organization's overall evaluation strategy and dashboards.
- Invite and encourage patient partners to give their perspectives on how to define and evaluate success
- Ensure that measurement/evaluation is a regular agenda item
- Produce an annual report that summarizes patient engagement processes and outcomes
- Close the loop with the patient partners by communicating how their feedback was used, actions taken, and any follow-up steps
- If you are responsible for monitoring or evaluating a safety or improvement project ensure a good fit between patient partners and the evaluation work/team and organize appropriate orientation



### Leaders

- Foster a learning culture that values monitoring and evaluation
- Educate the board and staff about standards for client and family-centred care
- Establish a baseline for measures in patient and family-centred care, and patient engagement using organizational assessment tools
- Include patient engagement, and patient and family-centred care key performance targets in organizational performance measures
- Integrate patient engagement evaluation into protocols, charters or terms of reference for committees that develop policy, redesign care processes, or improve quality and safety
  - Support measuring patient engagement quality and impact during planning, bringing in the perspectives of all involved (e.g., patients and family, providers, decision-makers)

## 4.6 Practice example

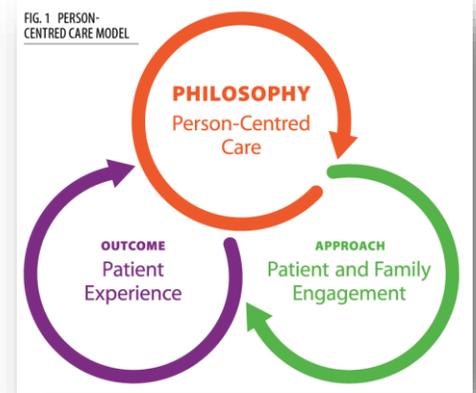
### Cancer Care Ontario

Evaluation is an integral element of engagement at Cancer Care Ontario which helped not only improve patient outcomes but also improve the engagement process.

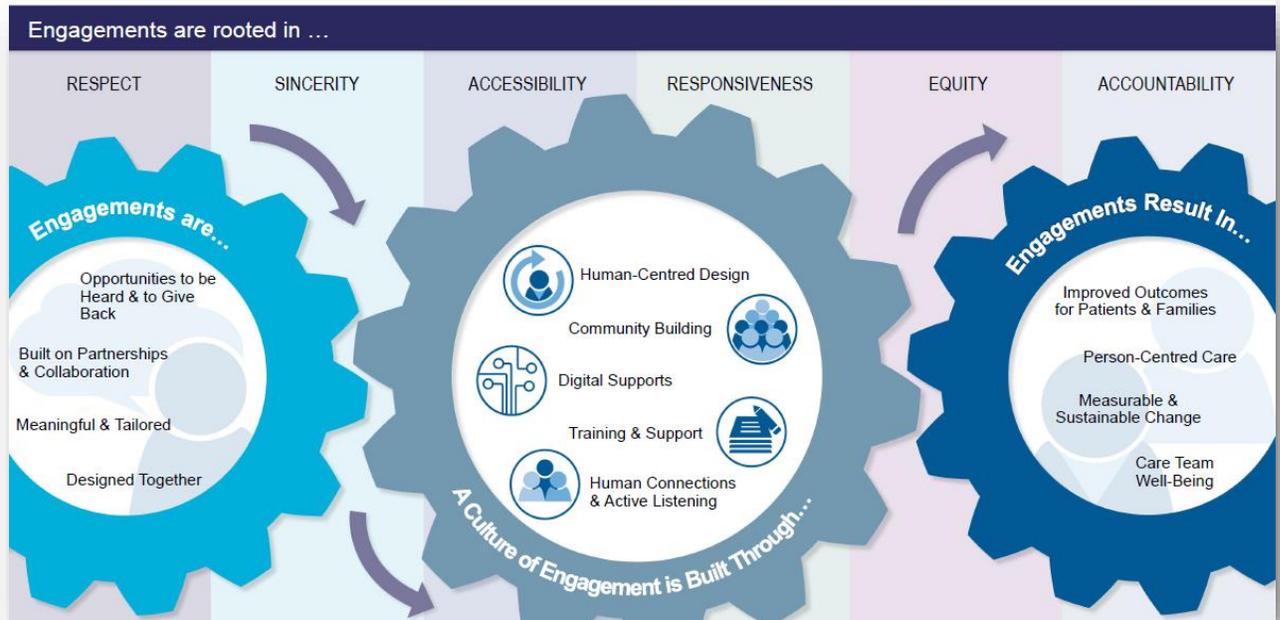
Several factors that contribute to that include<sup>27,113,117</sup>

- Clarifying terminology and linking different concepts – see the Person Centred Care Model
- Describe the link between engagement and outcomes – see the Engagement Model
- Engaging patient and family advisors in improving existing processes including the development of the engagement model
- Including evaluation as part of the Engagement Model Implementation
- Being inclusive of the needs and perspective of marginalized communities in order to develop a more equitable approach to cancer system planning and services – see the Equity in Engagement Framework and toolkit
- Sustaining and growing a patient and family advisor council (since 2011) and continuously assessing the impact and process of engagement

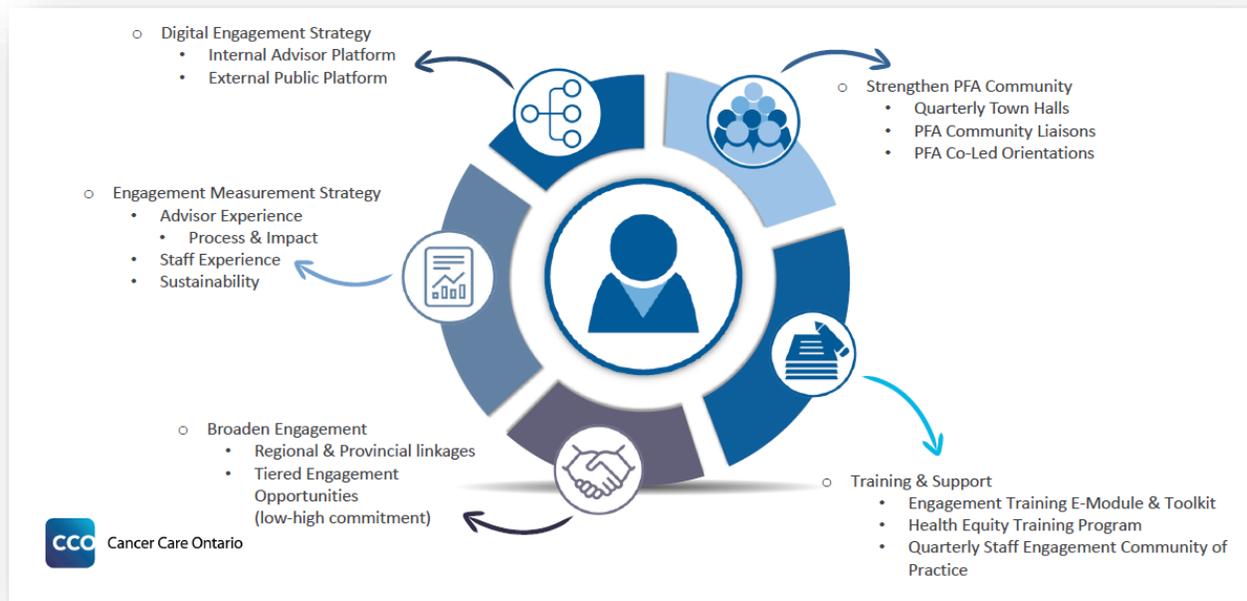
**Fig 1: Person-centred Care Model**



**Fig 2: Cancer Care Ontario Engagement Model**

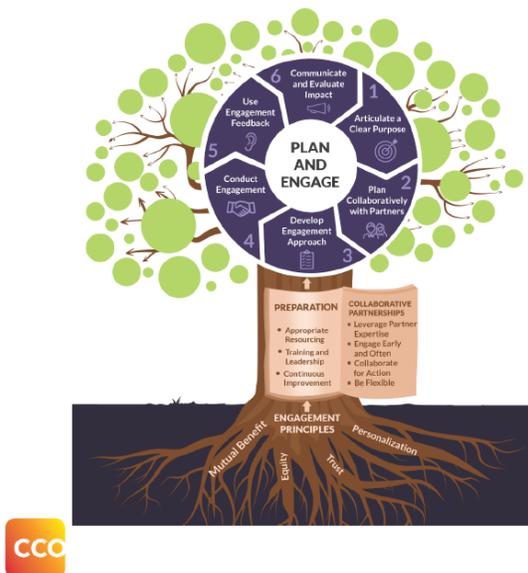


**Fig 3: Implementation of the Engagement Model**



**Fig 4: Equity in Engagement**

The components of the equity engagement framework are illustrated in the following diagram:



*The equity engagement framework has the same structure as a healthy, growing tree. At the roots are the engagement principles that set the foundation for the tree and ground your organization's engagement activities. The trunk acts as a stable space that prepares you internally for engagement and externally through collaborative partnerships to conduct equity-based engagement. All of this leads to the growth of healthy branches, that through the engagement process enable your organization to facilitate meaningful participation during the engagement process, with the outcome of more equitable engagement.*

## 5. Supporting References

- <sup>1</sup> Robert G. Organizational and Network Initiatives on Patient and Family Engagement that Accelerate Healthcare Improvement. In: Baker GR, Judd M, Maika C, eds. *Patient Engagement: Catalyzing Improvement and Innovation in Healthcare*. Toronto, ON: Longwoods Publishing Corporation; 2016:7-10. <https://www.longwoods.com/publications/books/24716>.
- <sup>2</sup> Cancer Care Ontario. *A Quality Initiative Endorsed by Cancer Care Ontario in Partnership with the Program in Evidence-Based Care (PEBC) Person-Centred Care Guideline*. Cancer Care Ontario; 2015. <https://www.cancercareontario.ca/en/files/pcc-guideline-full-guidancepdf>.
- <sup>3</sup> Schoen C, Osborn R. *The Commonwealth Fund 2012 International Health Policy Survey of Primary Care Physicians*. 2012.
- <sup>4</sup> Chan B, Cochrane D, Canadian Institute for Health Information, Canadian Patient Safety Institute. *Measuring Patient Harm in Canadian Hospitals*. Ottawa, ON: Canadian Institute for Health Information; 2016. [https://secure.cihi.ca/free\\_products/cihi\\_cpssi\\_hospital\\_harm\\_en.pdf](https://secure.cihi.ca/free_products/cihi_cpssi_hospital_harm_en.pdf).
- <sup>5</sup> Baker GR, Judd M, Fancott C, Maika C. Creating “Engagement-Capable Environments” in Healthcare. In: Baker GR, Judd M, Maika C, eds. *Patient Engagement: Catalyzing Improvement and Innovation in Healthcare*. Toronto, ON: Longwoods Publishing Corporation; 2016:18.
- <sup>6</sup> Health Canada. *Unleashing Innovation: Excellent Healthcare for Canada: Report of the Advisory Panel on Healthcare Innovation*. Ottawa, ON: Health Canada; 2015. <https://www.canada.ca/en/health-canada/services/publications/health-system-services/report-advisory-panel-healthcare-innovation.html>.
- <sup>7</sup> Carman KL, Dardess P, Maurer M, et al. Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies. *Health Aff (Millwood)*. 2013;32(2):223-231. doi:10.1377/hlthaff.2012.1133
- <sup>8</sup> Health Council of Canada. *Which Way to Quality? Key Perspectives on Quality Improvement in the Canadian Healthcare System*. Toronto, ON: Health Council of Canada; 2013. [https://healthcouncilcanada.ca/files/QIReport\\_ENG\\_FA.pdf](https://healthcouncilcanada.ca/files/QIReport_ENG_FA.pdf).
- <sup>9</sup> Patients for Patient Safety Canada. Patients for Patient Safety Canada. Canadian Patient Safety Institute. <https://www.patientsafetyinstitute.ca/en/About/Programs/ppsc/Pages/default.aspx>.
- <sup>10</sup> American Institutes for Research. A Roadmap for Patient and Family Engagement in Healthcare: Practice and Research. American Institutes for Research. <https://www.air.org/project/roadmap-guides-patient-and-family-engagement-healthcare/>. Published 2015.
- <sup>11</sup> Centers for Medicare and Medicaid Services. About the Partnership for Patients. CMS.gov, Centers for Medicare and Medicaid Services. <https://partnershipforpatients.cms.gov/about-the-partnership/aboutthepartnershipforpatients.html>. Published 2015.
- <sup>12</sup> Baker GR. *Evidence Boost: A Review of Research Highlighting How Patient Engagement Contributes to Improved Care*. Ottawa, ON: Canadian Foundation for Healthcare Improvement; 2014. <https://www.cfhi-fccss.ca/SearchResultsNews/2014/08/14/evidence-boost-a-review-of-research-highlighting-how-patient-engagement-contributes-to-improved-care>.
- <sup>13</sup> National Patient Safety Foundation’s Lucian Leape Institute. *Safety Is Personal: Partnering with Patients and Families for the Safest Care*. Boston, MA: National Patient Safety Foundation; 2014. <http://www.ihf.org/resources/Pages/Publications/Safety-Is-Personal-Partnering-with-Patients-and-Families-for-the-Safest-Care.aspx>.
- <sup>14</sup> Dentzer S. Rx for the “blockbuster drug” of patient engagement. *Health Aff Proj Hope*. 2013;32(2):202. doi:10.1377/hlthaff.2013.0037
- <sup>15</sup> Coulter A, Ellins J. Effectiveness of strategies for informing, educating, and involving patients. *BMJ*. 2007;335(7609):24. doi:10.1136/bmj.39246.581169.80
- <sup>16</sup> Kreindler SA. Patient involvement and the politics of methodology. *Can Public Adm*. 2009;52(1):113-124. doi:10.1111/j.1754-7121.2009.00062.x
- <sup>17</sup> Accreditation Canada. *Client- and Family-Centred Care in the Qmentum Program*. Accreditation Canada; 2015. <https://www.cfhi-fccss.ca/sf-docs/default-source/patient-engagement/accreditation-canada.pdf>.
- <sup>18</sup> Health Standards Organization. Standards Technical Committees & Working Groups. Health Standards Organization. <https://healthstandards.org/standards/technical-committees/>. Published January 13, 2017.

- <sup>19</sup> World Health Organization Secretariat. *Framework on Integrated, People-Centred Health Services*. World Health Organization; 2016. <https://www.who.int/servicedeliverysafety/areas/people-centred-care/framework/en/>.
- <sup>20</sup> Michael Smith Foundation for Health Research. *Developing MSFHR's Strategy for Public Involvement: Findings from an Environmental Scan*. Unpublished; 2016.
- <sup>21</sup> Institute for Patient and Family-Centered Care (IPFCC). About Us. Institute for Patient and Family-Centered Care (IPFCC). <https://ipfcc.org/about/index.html>.
- <sup>22</sup> Picker Institute. Picker Institute. Institute for Patient and Family-Centered Care (IPFCC). <https://www.ipfcc.org/resources/picker-institute.html>.
- <sup>23</sup> Institute for Healthcare Improvement. Person- and Family-Centered Care Initiatives. Institute for Healthcare Improvement. <http://www.ihl.org/Engage/Initiatives/PatientFamilyCenteredCare/Pages/default.aspx>.
- <sup>24</sup> The King's Fund. Patient engagement and involvement. The King's Fund. <https://www.kingsfund.org.uk/projects/gp-inquiry/patient-engagement-involvement>.
- <sup>25</sup> National Academy of Sciences. Crossing the Quality Chasm: The IOM Health Care Quality Initiative. <http://www.nationalacademies.org/hmd/Global/News%20Announcements/Crossing-the-Quality-Chasm-The-IOM-Health-Care-Quality-Initiative.aspx>.
- <sup>26</sup> Frampton SB, Guastello S, Hoy L, Naylor M, Sheridan S, Johnston-Fleece M. Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care. *Natl Acad Med Perspect*. 2017;Discussion Paper:1-38. doi:<https://doi.org/10.31478/201701f>
- <sup>27</sup> Cancer Care Ontario. Model for Engagement. *Unpublished*. 2019.
- <sup>28</sup> Dagnone T. *For Patients' Sake: Patient First Review Commissioner's Report to the Saskatchewan Minister of Health*. Regina, SK: Saskatchewan Ministry of Health; 2009. <https://www.saskatchewan.ca/government/health-care-administration-and-provider-resources/saskatchewan-health-initiatives/patient-first-review>.
- <sup>29</sup> Saskatchewan Health Quality Council. *HQC's Strategic Plan 2016–2019: Building Improvement Capability and Spreading Improvement in Healthcare*. Saskatoon, SK: Saskatchewan Health Quality Council; 2016. <https://hqc.sk.ca/Portals/0/HQC%20Strategic%20Plan%202016-2019.pdf?ver=2016-10-06-092247-097>.
- <sup>30</sup> Nova Scotia Health Authority. *Involving Patients and Citizens: A Review of Capital Health's Engagement Policy Achievements, 2010–2014*. Nova Scotia Health Authority; 2013. <http://www.cdha.nshealth.ca/involving-patients-citizens>.
- <sup>31</sup> Pomey M-P, Morin E, Neault C, et al. Patient Advisors: How to implement a process for involvement at all levels of governance in a healthcare organization. *Patient Exp J*. 2016;3(2):99-112. doi:10.35680/2372-0247.1134
- <sup>32</sup> Canadian Patient Safety Institute. Recognizing Excellence in Patient Engagement for Patient Safety. Canadian Patient Safety Institute. <https://www.patientsafetyinstitute.ca/en/events/patientchampionawards/Pages/default.aspx>. Published 2019.
- <sup>33</sup> Gandhi TK, Kaplan GS, Leape L, et al. Transforming concepts in patient safety: A progress report. *BMJ Qual Amp Saf*. 2018;27(12):1019. doi:10.1136/bmjqs-2017-007756
- <sup>34</sup> World Health Organization. *Global Action of Patient Safety*. Geneva, CH: World Health Organization; 2019. [https://apps.who.int/gb/ebwha/pdf\\_files/WHA72/A72\\_26-en.pdf](https://apps.who.int/gb/ebwha/pdf_files/WHA72/A72_26-en.pdf).
- <sup>35</sup> RiskAnalytica. *The Case of Investing in Patient Safety in Canada*. North York, ON: RiskAnalytica; 2017. <https://www.patientsafetyinstitute.ca/en/About/Documents/The%20Case%20for%20Investing%20in%20Patient%20Safety.pdf>.
- <sup>36</sup> IPSOS Public Affairs. *Patient Safety in Canada*. Toronto, ON: IPSOS; 2018. <https://www.patientsafetyinstitute.ca/en/toolsResources/Documents/Patient%20Harm%20Awareness%20-%20Ipsos/CPSI%20-%20Patient%20Safety%20in%20Canada%20Baseline%20Report.pdf#search=ipsos>.
- <sup>37</sup> Berger Z, Flickinger TE, Pfoh E, Martinez KA, Dy SM. Promoting engagement by patients and families to reduce adverse events in acute care settings: A systematic review. *BMJ Qual Amp Saf*. 2014;23(7):548. doi:10.1136/bmjqs-2012-001769
- <sup>38</sup> IMAGINE: Citizens Collaborating for Health. Five sources of evidence. <https://imaginecitizens.ca/learning-together/>.

- <sup>39</sup> Abelson J, Li K, Wilson G, Shields K, Schneider C, Boesveld S. Supporting quality public and patient engagement in health system organizations: Development and usability testing of the Public and Patient Engagement Evaluation Tool. *Health Expect*. 2016;19(4):817-827. doi:10.1111/hex.12378
- <sup>40</sup> Patients Canada. About Us. Patients Canada. <https://patientscanada.ca/about/>.
- <sup>41</sup> CHA Learning: HealthCareCAN. People-Centred Care Leadership Program. CHA Learning: HealthCareCAN. <https://www.chalearning.ca/programs-and-courses/people-centred-care/people-centred-care-leadership-program/>.
- <sup>42</sup> Baker G, Judd M, Maika C, eds. Appendix 2 – Table 2 – Examples of Impacts of Patient Engagement. In: *Patient Engagement: Catalyzing Improvement and Innovation in Healthcare*. Toronto, ON: Longwoods Publishing Corporation; 2016.
- <sup>43</sup> Hall J, Peat M, Birks Y, et al. Effectiveness of interventions designed to promote patient involvement to enhance safety: A systematic review. *Qual Saf Health Care*. 2010;19(5):e10. doi:10.1136/qshc.2009.032748
- <sup>44</sup> Weingart SN, Pagovich O, Sands DZ, et al. What can hospitalized patients tell us about adverse events? Learning from patient-reported incidents. *J Gen Intern Med*. 2005;20(9):830-836. doi:10.1111/j.1525-1497.2005.0180.x
- <sup>45</sup> Weissman JS, Schneider EC, Weingart SN, et al. Comparing Patient-Reported Hospital Adverse Events with Medical Record Review: Do Patients Know Something That Hospitals Do Not? *Ann Intern Med*. 2008;149(2):100-108. doi:10.7326/0003-4819-149-2-200807150-00006
- <sup>46</sup> Charmel PA, Frampton SB. Building the business case for patient-centered care. *Healthc Financ Manag J Healthc Financ Manag Assoc*. 2008;62(3):80-85.
- <sup>47</sup> Epstein RM, Street RL. *Patient-Centered Care for the 21st Century: Physicians' Roles, Health Systems and Patients' Preferences*. Philadelphia, PA: American Board of Internal Medicine Foundation; 2008.
- <sup>48</sup> Steffens L, Jaeger S, Herrmann S, Thomas K, Barker K, Eggleston A. Hospital readmission: The move toward pay for performance. *J Nurs Adm*. 2009;39(11):462-464. doi:10.1097/NNA.0b013e3181bd5ec0
- <sup>49</sup> Khan A, Coffey M, Litterer KP, et al. Families as Partners in Hospital Error and Adverse Event Surveillance. *JAMA Pediatr*. 2017;171(4):372-381. doi:10.1001/jamapediatrics.2016.4812
- <sup>50</sup> Lachman P, Linkson L, Evans T, Clausen H, Hothi D. Developing person-centred analysis of harm in a paediatric hospital: A quality improvement report. *BMJ Qual Amp Saf*. 2015;24(5):337. doi:10.1136/bmjqs-2014-003795
- <sup>51</sup> Landers T, Abusalem S, Coty M-B, Bingham J. Patient-centered hand hygiene: The next step in infection prevention. *Am J Infect Control*. 2012;40(4 Suppl 1):S11-17. doi:10.1016/j.ajic.2012.02.006
- <sup>52</sup> Institute for Patient- and Family-Centered Care. *Strategically Advancing Patient and Family Advisory Councils in New York State Hospitals*. New York, NY: NYS Health Foundation; 2018. [https://www.ipfcc.org/bestpractices/NYSHF\\_2018\\_PFAC\\_Online\\_v3.pdf](https://www.ipfcc.org/bestpractices/NYSHF_2018_PFAC_Online_v3.pdf).
- <sup>53</sup> Trew M, Nettleton S, Flemons W. *Harm to Healing – Partnering with Patients Who Have Been Harmed*. Edmonton, AB: Canadian Patient Safety Institute; 2010.
- <sup>54</sup> McGann P. Where we are, where we are heading, and how you can 'ramp up' your influence on health system transformation - A.k.a. "Delivery system reform - DSR". Presented at the: PFCC Partners Patient and Family Advocate Summit; October 27, 2015; Los Angeles, CA.
- <sup>55</sup> Coulter A. Patient Engagement—What Works? *J Ambulatory Care Manage*. 2012;35(2). [https://journals.lww.com/ambulatorycaremanagement/Fulltext/2012/04000/Patient\\_Engagement\\_What\\_Works\\_.3.aspx](https://journals.lww.com/ambulatorycaremanagement/Fulltext/2012/04000/Patient_Engagement_What_Works_.3.aspx).
- <sup>56</sup> Archambault PM, McGavin C, Dainty KN, et al. Recommendations for patient engagement in patient-oriented emergency medicine research. *CJEM*. 2018;20(3):435-442. doi:10.1017/cem.2018.370
- <sup>57</sup> Forsythe L, Heckert A, Margolis MK, Schrandt S, Frank L. Methods and impact of engagement in research, from theory to practice and back again: Early findings from the Patient-Centered Outcomes Research Institute. *Qual Life Res*. 2018;27(1):17-31. doi:10.1007/s11136-017-1581-x
- <sup>58</sup> Domecq JP, Prutsky G, Elraiyah T, et al. Patient engagement in research: A systematic review. *BMC Health Serv Res*. 2014;14(1):89. doi:10.1186/1472-6963-14-89
- <sup>59</sup> Kovacs Burns K. Canadian patient safety champions: Collaborating on improving patient safety. *Healthc Q Tor Ont*. 2008;11(3 Spec No.):95-100.

- <sup>60</sup> Wayman KI. *Creating and Sustaining Effective Hospital Family Advisory Councils: Findings from the California Patient and Family Centered Care Network of Pediatric Hospitals*. Lucile Packard Children's Hospital Stanford; 2015. [https://www.lpfch.org/sites/default/files/field/publications/creating\\_and\\_sustaining\\_effective\\_hospital\\_family\\_advisory\\_councils.pdf](https://www.lpfch.org/sites/default/files/field/publications/creating_and_sustaining_effective_hospital_family_advisory_councils.pdf).
- <sup>61</sup> New L, Goodridge D, Kappel J, Groot G, Dobson R. "I just have to take it" – patient safety in acute care: Perspectives and experiences of patients with chronic kidney disease. *BMC Health Serv Res*. 2019;19(1):199. doi:10.1186/s12913-019-4014-4
- <sup>62</sup> Moore C, Sarnoff Lee B, Gonchar R, Israel Deaconess B, Berry-Berard L, Seely M. Voices of Experience: Advisors Rounding on Patients in the Hospital. Presented at the: International Conference on Patient- and Family-Centered Care; July 27, 2016; New York, NY.
- <sup>63</sup> Sign up to Safety Patient Engagement in Patient Safety Group, Yorkshire Quality and Safety Research Group, Valid Research Ltd. *Patient Engagement in Patient Safety: A Framework for the NHS*. Sign up to Safety; 2016. <https://www.england.nhs.uk/signuptosafety/wp-content/uploads/sites/16/2016/05/pe-ps-framwrk-apr-16.pdf>.
- <sup>64</sup> Patients for Patient Safety Canada. PFPSC Background/History. Canadian Patient Safety Institute. <https://www.patientsafetyinstitute.ca/en/About/Programs/PPSC/Pages/History.aspx>.
- <sup>65</sup> The Social Transformation Project. The Wheel of Change for Organizations. [http://www.biohabitats.com/wp-content/uploads/WheelOfChange\\_Organizations\\_v7-copy.jpg](http://www.biohabitats.com/wp-content/uploads/WheelOfChange_Organizations_v7-copy.jpg).
- <sup>66</sup> Canadian Patient Safety Institute. Patient safety and incident management toolkit: Patient Safety Culture. Canadian Patient Safety Institute. <https://www.patientsafetyinstitute.ca/en/toolsResources/PatientSafetyIncidentManagementToolkit/PatientSafetyManagement/Pages/Patient-Safety-Culture.aspx>.
- <sup>67</sup> Singer SJ, Vogus TJ. Reducing Hospital Errors: Interventions that Build Safety Culture. *Annu Rev Public Health*. 2013;34(1):373-396. doi:10.1146/annurev-publhealth-031912-114439
- <sup>68</sup> Shortell SM, Singer SJ. Improving Patient Safety by Taking Systems Seriously. *JAMA*. 2008;299(4):445-447. doi:10.1001/jama.299.4.445
- <sup>69</sup> Illingworth J. *Continuous Improvement of Patient Safety: The Case for Change in the NHS*. London, UK: The Health Foundation; 2015. <https://www.health.org.uk/sites/default/files/ContinuousImprovementPatientSafety.pdf>.
- <sup>70</sup> Alvesson M, Sveningsson S. *Changing Organizational Culture: Cultural Change Work in Progress*. London, UK: Routledge; 2015.
- <sup>71</sup> Vigneault K, Biron A, Simony E. An integrated approach to patient engagement in quality improvement. Presented at the: International Conference on Patient and Family-Centered Care; July 25, 2016; New York, NY.
- <sup>72</sup> Edmondson A. *The Fearless Organization: Creating Psychological Safety in the Workplace for Learning, Innovation, and Growth*. Hoboken, NJ: John Wiley & Sons; 2018.
- <sup>73</sup> Agency for Healthcare Research and Quality. *Supporting Patient and Family Engagement: Best Practices for Hospital Leaders*. Agency for Healthcare Research and Quality [https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/howtogetstarted/Best\\_Practices\\_Hosp\\_Leaders\\_508.pdf](https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/howtogetstarted/Best_Practices_Hosp_Leaders_508.pdf).
- <sup>74</sup> Alberta Health Services. Vision, Mission, Values & Strategies. Alberta Health Services. <https://www.albertahealthservices.ca/about/Page190.aspx>.
- <sup>75</sup> Baker GR, Fancott C, Judd M, O'Connor P. Expanding patient engagement in quality improvement and health system redesign: Three Canadian case studies. *Healthc Manage Forum*. 2016;29(5):176-182. doi:10.1177/0840470416645601
- <sup>76</sup> Bishop AC, Macdonald M. Patient Involvement in Patient Safety: A Qualitative Study of Nursing Staff and Patient Perceptions. *J Patient Saf*. 2017;13(2). [https://journals.lww.com/journalpatientsafety/Fulltext/2017/06000/Patient\\_Involvement\\_in\\_Patient\\_Safety\\_\\_A.5.aspx](https://journals.lww.com/journalpatientsafety/Fulltext/2017/06000/Patient_Involvement_in_Patient_Safety__A.5.aspx).
- <sup>77</sup> Johnson B, Abraham M, Conway J, et al. *Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities*. Bethesda, MD: Institute for Family-Centered Care; 2008. [http://www.hqontario.ca/Portals/0/modals/qi/en/processmap\\_pdfs/articles/partnering%20with%20patients%20and%20families%20to%20design%20a%20patient-%20and%20family-centered%20health%20care%20system.pdf](http://www.hqontario.ca/Portals/0/modals/qi/en/processmap_pdfs/articles/partnering%20with%20patients%20and%20families%20to%20design%20a%20patient-%20and%20family-centered%20health%20care%20system.pdf).
- <sup>78</sup> Shaller D, Darby C. *High-Performing Patient- and Family-Centered Academic Medical Centers: Cross-Site Summary of Six Case Studies*. Camden, ME: Picker Institute Inc.; 2009.

- <sup>79</sup> Berman S. Why human resources policies and practices are critical to improving the patient experience. *Patient Exp J*. 2016;3(2):9-11. doi:10.35680/2372-0247.1187
- <sup>80</sup> Institute for Patient- and Family-Centered Care. *Advancing the Practice of Patient and Family-Centered Care in Hospitals: How to Get Started – Human Resources Checklist*. Bethesda, MD: Institute of Patient and Family-Centered Care.; 2017. [http://ipfcc.org/resources/getting\\_started.pdf](http://ipfcc.org/resources/getting_started.pdf).
- <sup>81</sup> Disclosure Working Group. *Canadian Disclosure Guidelines: Being Open with Patients and Families*. Edmonton, AB: Canadian Patient Safety Institute; 2011:4. <https://www.patientsafetyinstitute.ca/en/toolsresources/disclosure/pages/default.aspx>.
- <sup>82</sup> Canadian Patient Safety Institute. Shift to Safety. Canadian Patient Safety Institute. <https://www.patientsafetyinstitute.ca/en/About/Programs/shift-to-safety/Pages/public.aspx>.
- <sup>83</sup> Le-Abuyen S, Ng J, Kim S, et al. Patient-as-observer approach: An alternative method for hand hygiene auditing in an ambulatory care setting. *Am J Infect Control*. 2014;42(4):439-442. doi:10.1016/j.ajic.2013.12.003
- <sup>84</sup> Public Health Ontario. Just Clean Your Hands – Hospitals: Training and tools. Public Health Ontario. [https://www.publichealthontario.ca/en/Health\\_Topics/Infection\\_Prevention\\_Control/Hand\\_Hygiene/JCYH\\_Hospitals](https://www.publichealthontario.ca/en/Health_Topics/Infection_Prevention_Control/Hand_Hygiene/JCYH_Hospitals).
- <sup>85</sup> Canadian Patient Safety Institute. Hand Hygiene Observation Tools. Canadian Patient Safety Institute. <https://www.patientsafetyinstitute.ca/en/toolsResources/pages/hand-hygiene-observation-tools.aspx>.
- <sup>86</sup> Watkins JD, Roberts DE, Williams TF, Martin DA, Coyle V. Observation of Medication Errors Made by Diabetic Patients in the Home. *Diabetes*. 1967;16(12):882. doi:10.2337/diab.16.12.882
- <sup>87</sup> Young K, Cochran K, Mei M, Adkins-Bley K, Ciarkowski S, Wagner D. Ensuring Safe Medication Administration through Direct Observation. *Qual Prim Care*. 2015;23(3):167-173.
- <sup>88</sup> The Joint Commission, World Health Organization. *Patient Identification*. Geneva, CH: World Health Organization; 2007. <https://www.who.int/patientsafety/solutions/patientsafety/PS-Solution2.pdf>.
- <sup>89</sup> The Institute for Safe Medication Practices Canada, The Healthcare Insurance Reciprocal of Canada. Analysis of Harmful Medication Incidents Involving Psychotropic Medications. *ISMP Can Saf Bull*. 2012;12(2). [https://www.ismp-canada.org/download/safetyBulletins/2012/ISMPCSB2012-02\\_Analysis\\_of\\_Harmful\\_Med\\_Incidents\\_Involving\\_Psychotropic\\_Meds.pdf](https://www.ismp-canada.org/download/safetyBulletins/2012/ISMPCSB2012-02_Analysis_of_Harmful_Med_Incidents_Involving_Psychotropic_Meds.pdf).
- <sup>90</sup> Canadian Patient Safety Institute, Canadian College of Health Leaders, HealthCareCAN, Healthcare Insurance Reciprocal of Canada. *Patient Safety Culture “Bundle” for CEO’s/Senior Leaders*. Canadian Patient Safety Institute; 2018. <https://www.patientsafetyinstitute.ca/en/toolsResources/Patient-Safety-Culture-Bundle/Pages/default.aspx>.
- <sup>91</sup> Manitoba Institute for Patient Safety. It’s Safe to Ask. Manitoba Institute for Patient Safety. <https://www.safetoask.ca/>.
- <sup>92</sup> Byrd J, Thompson L. “It’s safe to ask”: Promoting patient safety through health literacy. *Healthc Q Tor Ont*. 2008;11(3 Spec No.):91-94.
- <sup>93</sup> Pomey M-P, Ghadiri DP, Karazivan P, Fernandez N, Clavel N. Patients as Partners: A Qualitative Study of Patients’ Engagement in Their Health Care. *PLOS ONE*. 2015;10(4):e0122499. doi:10.1371/journal.pone.0122499
- <sup>94</sup> O’Daniel M, Rosenstein AH. Professional Communication and Team Collaboration. In: Hughes RG, ed. *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*. Rockville (MD): Agency for Healthcare Research and Quality (US); 2008.
- <sup>95</sup> Health Quality Ontario. *Team Building Resource Guide for Ontario Primary Health Care Teams*. Toronto, ON: Health Quality Ontario; 2012. <http://www.hqontario.ca/Portals/0/documents/qi/pc-team-building-guide-intro-en.pdf>.
- <sup>96</sup> Canadian Patient Safety Institute. Topics. Canadian Patient Safety Institute. <https://www.patientsafetyinstitute.ca/en/topic/Pages/default.aspx#MedicationSafety>.
- <sup>97</sup> Canadian Foundation for Healthcare Improvement. The power of partnerships: Patients and staff co-designing bedside care. Presented at the: Fuel the Innovation Conversation; December 28, 2016. <http://www.cfhi-fcass.ca/sf-docs/default-source/on-call/oncall-sept28-2016-e.pdf?sfvrsn=2>.
- <sup>98</sup> Manitoba Institute for Patient Safety., Regional Health Authorities of Manitoba, Winnipeg Regional Health Authority, Government of Manitoba. *The Facts about Critical Incident Reporting and Disclosure*. Winnipeg, MB: Manitoba Institute for Patient Safety. 2010. <https://www.gov.mb.ca/health/patientsafety/docs/pamphlet.pdf>.

- <sup>99</sup> Chan A-W, Altman DG. Identifying outcome reporting bias in randomised trials on PubMed: Review of publications and survey of authors. *BMJ*. 2005;330(7494):753. doi:10.1136/bmj.38356.424606.8F
- <sup>100</sup> Emanuel LL, Taylor L, Hain A, et al., eds. The Patient Safety Education Program – Canada (PSEP – Canada) Curriculum. 2016. <http://www.patientsafetyinstitute.ca/en/education/patientsafetyeducationprogram/patientsafetyeducationcurriculum/pages/default.aspx>.
- <sup>101</sup> Hardavella G, Aamli-Gagnat A, Frille A, Saad N, Niculescu A, Powell P. Top tips to deal with challenging situations: Doctor–patient interactions. *Breathe*. 2017;13(2):129. doi:10.1183/20734735.006616
- <sup>102</sup> O’Connor E, Coates HM, Yardley IE, Wu AW. Disclosure of patient safety incidents: A comprehensive review. *Int J Qual Health Care*. 2010;22(5):371-379. doi:10.1093/intqhc/mzq042
- <sup>103</sup> Workman T. *Addendum to the PfP PFE Strategic Vision and Roadmap: Defining the Person and Family Engagement (PFE) Metrics for Improved Measurement: Purpose and Intention of the Five PFE Metrics*. Washington, DC: American Institutes for Research; 2016. <http://www.hret-hiin.org/Resources/pfe/16/Addendum-to-Roadmap-PFPDefinitions-20160523.pdf>.
- <sup>104</sup> Institute for Patient and Family-Centered Care (IPFCC). Metrics/Sample Dashboard. <http://www.ipfcc.org/bestpractices/strategies-for-changing-policies.html>.
- <sup>105</sup> Dubrovsky AS, Bishop A, Biron A, et al. “We Should Talk” —Moving knowledge into action by learning to engage patients, families, and healthcare staff to communicate for patient safety. *Health Manage Forum*. 2016;29(4):141-145. doi:10.1177/0840470416641119
- <sup>106</sup> Reinertsen JL, Bisognano M, Pugh MD. *Seven Leadership Leverage Points for Organization-Level Improvement in Health Care (Second Edition)*. Cambridge, MA: Institute for Healthcare Improvement; 2008. <http://www.ihl.org/resources/Pages/IHIWhitePapers/SevenLeadershipLeveragePointsWhitePaper.aspx>.
- <sup>107</sup> Saskatchewan Health: Putting Patients First, Canadian Foundation for Healthcare Improvement. *Patient Family Advisor: Handbook*. Saskatchewan Health [https://hqc.sk.ca/Portals/0/documents/HQC0709\\_PFA\\_Booklet\\_revised.pdf](https://hqc.sk.ca/Portals/0/documents/HQC0709_PFA_Booklet_revised.pdf).
- <sup>108</sup> Health Research & Educational Trust. *Partnering to Improve Quality and Safety: A Framework for Working with Patient and Family Advisors*. Chicago, IL: Health Research & Educational Trust; 2015. <http://www.hpoe.org/resources/ahahret-guides/1828>.
- <sup>109</sup> Sharma AE, Grumbach K. Engaging patients in primary care practice transformation: Theory, evidence and practice. *Fam Pract*. 2016;34(3):262-267. doi:10.1093/fampra/cmw128
- <sup>110</sup> Institute for Patient and Family Centred Care. *Staff Liaison for Patient and Family Advisory Councils and Other Collaborative Endeavours*. Bethesda, MD: Institute for Patient and Family Centred Care. 2010. [http://www.ipfcc.org/resources/Staff\\_Liaison.pdf](http://www.ipfcc.org/resources/Staff_Liaison.pdf).
- <sup>111</sup> Université de Montréal. *Pratique Collaborative et Partenariat Patient En Santé et Services Sociaux – Référentiel de Compétences*. Montréal, QC: Université de Montréal; 2018. [https://medfam.umontreal.ca/wp-content/uploads/sites/16/2018/04/Referentiel-pratique\\_Collaborative-et-partenariatPatient\\_28-10-2016.pdf](https://medfam.umontreal.ca/wp-content/uploads/sites/16/2018/04/Referentiel-pratique_Collaborative-et-partenariatPatient_28-10-2016.pdf).
- <sup>112</sup> BC Patient Safety & Quality Council. What Matters to You? / BC Patient Safety & Quality Council. BC Patient Safety & Quality Council. <https://bcpsqc.ca/advance-the-patient-voice/what-matters-to-you/>.
- <sup>113</sup> Cancer Care Ontario. *Equity in Engagement Framework*. Toronto, ON: Cancer Care Ontario [https://www.cfhi-fcss.ca/sf-docs/default-source/newsevents/diversity-pe-learning-2019/dle-2019-equity-in-engagement-framework-e.pdf?sfvrsn=b710ad44\\_2](https://www.cfhi-fcss.ca/sf-docs/default-source/newsevents/diversity-pe-learning-2019/dle-2019-equity-in-engagement-framework-e.pdf?sfvrsn=b710ad44_2).
- <sup>114</sup> Health Quality Ontario. *Recruiting for Diversity. Guide for Creating and Sustaining Patient and Family Advisory Councils*. Toronto, ON: Health Quality Ontario; 2016. <http://www.hqontario.ca/Portals/0/documents/pe/recruiting-diversity-en.pdf>.
- <sup>115</sup> Tambuyzer E, Pieters G, Van Audenhove C. Patient involvement in mental health care: One size does not fit all. *Health Expect Int J Public Particip Health Care Health Policy*. 2014;17(1):138-150. doi:10.1111/j.1369-7625.2011.00743.x
- <sup>116</sup> Government of Victoria Department of Education and Early Childhood Development. *Stakeholder Engagement Framework*. Melbourne, AU: Government of Victoria; 2011.
- <sup>117</sup> Cancer Care Ontario. *Improving Ontario’s Health System through Patient and Family Engagement*. Toronto, ON: Cancer Care Ontario <https://www.ccohealth.ca/sites/CCOHealth/files/assets/CCOPatientEngagementReport.pdf>.
- <sup>118</sup> Boivin A, Lehoux P, Burgers J, Grol R. What Are the Key Ingredients for Effective Public Involvement in Health Care Improvement and Policy Decisions? A Randomized Trial Process Evaluation. *Milbank Q*. 2014;92(2):319-350. doi:10.1111/1468-0009.12060

- <sup>119</sup> Vigod S, Hussain-Shamsy N, Grigoriadis S, et al. A patient decision aid for antidepressant use in pregnancy: Study protocol for a randomized controlled trial. *Trials*. 2016;17(1):110. doi:10.1186/s13063-016-1233-4
- <sup>120</sup> Coulter A. *Leadership for Patient Engagement*. London, UK: The King's Fund; 2012. <http://www.kingsfund.org.uk/sites/files/kf/leadership-patient-engagement-angela-coulter-leadership-review2012-paper.pdf>.
- <sup>121</sup> Health Quality Ontario. *Engaging with Patients: Stories and Successes from the 2015/16 Quality Improvement Plan*. Toronto, ON: Health Quality Ontario; 2016. <http://www.hqontario.ca/portals/0/documents/qi/qip/engaging-with-patients-en.pdf>.
- <sup>122</sup> Yu A, Flott K, Chainani N, Fontana G, Darzi A. *Patient Safety 2030*. London, UK: NIHR Imperial Patient Safety Translational Research Centre; 2016. <https://www.imperial.ac.uk/media/imperial-college/institute-of-global-health-innovation/centre-for-health-policy/Patient-Safety-2030-Report-VFinal.pdf>.
- <sup>123</sup> Brosseau M, Gagnon D, Rohde K, Schellinck J. Integrating Engagement and Improvement Work in a Pediatric Hospital. *Healthc Q*. 2017;20(1):67-72. doi:10.12927/hcq.2017.25071
- <sup>124</sup> Health Quality Ontario. *Quality Improvement Plan (QIP) Guidance Document for Ontario's Health Care Organizations*. Toronto, ON: Health Quality Ontario; 2015. <http://www.hqontario.ca/portals/0/Documents/qi/qip-guidance-document-1511-en.pdf>.
- <sup>125</sup> Plsek PE. Using patient experience to drive innovation. In: *Accelerating Health Care Transformation with Lean and Innovation: The Virginia Mason Experience*. Boca Raton, FL: CRC Press; 2014:145-165.
- <sup>126</sup> Alberta Health Services. AHS Improvement Way (AIW) A3 Worksheet.
- <sup>127</sup> Neuwirth EB, Bellows J, Jackson AH, Price PM. How Kaiser Permanente Uses Video Ethnography Of Patients For Quality Improvement, Such As In Shaping Better Care Transitions. *Health Aff (Millwood)*. 2012;31(6):1244-1250. doi:10.1377/hlthaff.2012.0134
- <sup>128</sup> Rohde K, Brosseau M, Gagnon D, Schellinck J, Kouri C. Envisioning mechanisms for success: Evaluation of EBCD at CHEO. *Patient Exp J*. 2016;3(2):113-129.
- <sup>129</sup> Bate P, Robert G. *Bringing User Experience to Healthcare Improvement: The Concepts, Methods and Practices of Experience-Based Design*. 1st ed. Boca Raton, FL: CRC Press; 2007.
- <sup>130</sup> Kovacs Burns K, George M, Masuda C, Louie L, Myers J, Brock T. Acting on Real-Time Patient Reports to Improve Safety. Presented at the: Patients for Patient Safety Webinar; July 27, 2018. <https://www.patientsafetyinstitute.ca/en/toolsResources/Pages/Acting-on-Real-Time-Patient-Reports-to-Improve-Safety.aspx>.
- <sup>131</sup> Schneider EC, Ridgely MS, Quigley DD, et al. *Developing and Testing the Health Care Safety Hotline: A Prototype Consumer Reporting System for Patient Safety Events. Final Report (Prepared by RAND Corporation under Contract HHS A290201000017I)*. Rockville, MD: Agency for Healthcare Research and Quality; 2016. <https://www.ahrq.gov/patient-safety/reports/hotline.html>.
- <sup>132</sup> Millman EA, Pronovost PJ, Makary MA, Wu AW. Patient-assisted incident reporting: Including the patient in patient safety. *J Patient Saf*. 2011;7(2):106-108. doi:10.1097/PTS.0b013e31821b3c5f
- <sup>133</sup> Faultner J, Kalbach S. Involving Patients and Families in Every Serious Safety Event Review. Presented at the: International Conference on Patient and Family-Centered Care Conference; July 25, 2016; New York, NY.
- <sup>134</sup> Canadian Patient Safety Institute, Institute for Safe Medication Practices Canada, Saskatchewan Health, et al. *Canadian Incident Analysis Framework*. Edmonton, AB: Canadian Patient Safety Institute; 2012. <https://www.patientsafetyinstitute.ca/en/toolsResources/IncidentAnalysis/Documents/Canadian%20Incident%20Analysis%20Framework.PDF>.
- <sup>135</sup> Duchscherer C, Davies JM. *Systematic Systems Analysis: A Practical Approach to Patient Safety Review*. Calgary, AB: Health Quality Council of Alberta; 2012. [https://d10k7k7mywg42z.cloudfront.net/assets/5501df86c0d67106cf02ae61/HQCA\\_SSA\\_PSR\\_111913.pdf](https://d10k7k7mywg42z.cloudfront.net/assets/5501df86c0d67106cf02ae61/HQCA_SSA_PSR_111913.pdf).
- <sup>136</sup> Etchegaray JM, Ottosen MJ, Aigbe A, et al. Patients as Partners in Learning from Unexpected Events. *Health Serv Res*. 2016;51 Suppl 3:2600-2614. doi:10.1111/1475-6773.12593
- <sup>137</sup> The Health Foundation. *Evidence Scan: Involving Patients in Improving Safety*. London, UK: The Health Foundation; 2013. <https://www.health.org.uk/sites/default/files/InvolvingPatientsInImprovingSafety.pdf>.
- <sup>138</sup> Healthcare Safety Investigation Branch. For patients, families and carers. Healthcare Safety Investigation Branch. <https://www.hsib.org.uk/public-patients/>.

- <sup>139</sup> Judd M, O'Connor P, Humphrey A. Rethinking 'patient engagement' evaluation: A mixed methods approach to measuring the impact of partnering with patients and families in quality improvement. Presented at the: International Conference on Patient and Family-Centered Care; July 26, 2016; New York, NY.
- <sup>140</sup> Shippee ND, Domecq Garces JP, Prutsky Lopez GJ, et al. Patient and service user engagement in research: A systematic review and synthesized framework. *Health Expect.* 2015;18(5):1151-1166. doi:10.1111/hex.12090
- <sup>141</sup> Canadian Evaluation Society. *What Is Evaluation?* Renfrew, Ontario: Canadian Evaluation Society; 2015. [https://evaluationcanada.ca/sites/default/files/definition\\_of\\_evaluation\\_20150714-1\\_en.pdf](https://evaluationcanada.ca/sites/default/files/definition_of_evaluation_20150714-1_en.pdf).
- <sup>142</sup> Patton MQ. *Utilization-Focused Evaluation*. Thousand Oaks, CA: Sage Publications; 2008.
- <sup>143</sup> Pomey M-P, Morin E. Developing a tool to measure patient partnership at the clinical and organizational level. Presented at the: International Conference on Patient- and Family-Centered Care; July 26, 2016; New York, NY.
- <sup>144</sup> BetterEvaluation. *The Rainbow Framework*. BetterEvaluation; 2014. <http://www.betterevaluation.org/sites/default/files/Rainbow%20Framework.pdf>.
- <sup>145</sup> BetterEvaluation. *Define What Is to Be Evaluated*. BetterEvaluation; 2013. <http://www.betterevaluation.org/sites/default/files/Define%20-%20Compact.pdf>.
- <sup>146</sup> Faculty of Health Sciences: Public & Patient Engagement. Public & Patient Engagement Evaluation Tool. McMaster University. <https://healthsci.mcmaster.ca/ppe/our-products/public-patient-engagement-evaluation-tool>.
- <sup>147</sup> Pomey MP. *Questionnaire for Healthcare Providers to Evaluate Patient Advisors' Participation*. Montréal, QC: University of Montréal; 2017.
- <sup>148</sup> Centre of Excellence on Partnerships with Patients and the Public. Patient and Public Engagement Evaluation Toolkit. CEPPP | Centre of Excellence on Partnership with Patients and the Public. <https://ceppp.ca/en/collaborations/evaluation-toolkit/>.
- <sup>149</sup> de Silva D. *Helping Measure Person-Centered Care: A Review of Evidence about Commonly Used Approaches and Tools Used to Help Measure Person-Centred Care*. London, UK: The Health Foundation; 2014. <https://www.health.org.uk/sites/default/files/HelpingMeasurePersonCentredCare.pdf>.
- <sup>150</sup> American Institutes for Research. Center for Patient & Consumer Engagement: Patient and Family Engagement Measure Inventory. American Institutes for Research. <https://aircpce.org/pfe-measure-tool>.
- <sup>151</sup> Institute for Healthcare Improvement, National Initiative of Children's Healthcare Quality, Institute for Family-Centered Care. *Patient- and Family-Centered Care Organizational Self-Assessment Tool*. Bethesda, MD: Institute for Family-Centered Care <https://www.patientsafetyinstitute.ca/en/toolsResources/GovernancePatientSafety/AssessImprovePatientSafetyCulture/Documents/Organizational%20Assessment.pdf>.
- <sup>152</sup> Frampton S, Guastello S, Brady C, et al. *Patient-Centered Care Improvement Guide*. Derby, CT: Planetree, Inc. & Camden, ME: Picker Institute; 2008. <http://patient-centeredcare.org/>.
- <sup>153</sup> Institute for Patient and Family-Centered Care. *A Hospital Self-Assessment Inventory*. Bethesda, MD: Institute for Patient and Family-Centered Care [https://resources.ipfcc.org/product\\_p/sat01.htm](https://resources.ipfcc.org/product_p/sat01.htm).
- <sup>154</sup> Gordon and Betty Moore Foundation, American Institutes for Research. Roadmap Guides Patient and Family Engagement in Healthcare. American Institutes for Research. <https://www.air.org/project/roadmap-guides-patient-and-family-engagement-healthcare>. Published 2016.
- <sup>155</sup> Elwin G. CollaboRATE, Measurement tool developed by a research group at Dartmouth Institute for Healthcare and Clinical Practice, Dartmouth College. <http://www.collaboratescore.org/collaborate-measure.html>.
- <sup>156</sup> Johnson BH. Measuring patient- and family-centered practice and the partnerships with patients and families. Presented at the: International Conference on Patient and Family-Centered Care; July 25, 2016; New York, NY.
- <sup>157</sup> OECD. Patient Safety. OECD. <http://www.oecd.org/health/patient-safety.htm>.
- <sup>158</sup> Canadian Institute of Health Information. Canadian preliminary care patient-reported experience measures. <https://www.cihi.ca/en/patient-experience>.

- <sup>159</sup> Canadian Institute of Health Information. Canadian patient experiences survey inpatient care and the Canadian patient experiences reporting system. Canadian Institute of Health Information. <https://www.cihi.ca/en/patient-experience>.
- <sup>160</sup> Health Quality Ontario. Quality Improvement in Primary Care. Health Quality Ontario. <https://www.hqontario.ca/Quality-Improvement/Quality-Improvement-in-Action/Quality-Improvement-in-Primary-Care>.
- <sup>161</sup> Health Research & Educational Trust. *A Leadership Resource for Patient and Family Engagement Strategies*. Chicago, IL: Health Research & Educational Trust; 2013. [http://www.hpoe.org/Reports-HPOE/Patient\\_Family\\_Engagement\\_2013.pdf](http://www.hpoe.org/Reports-HPOE/Patient_Family_Engagement_2013.pdf).
- <sup>162</sup> Joint Commission Resources. *Checklist to Improve Effective Communication, Cultural Competence, and PFCC*. Oak Brook, IL: Joint Commission Resources <http://www.jcrinc.com/checklist-to-improve-effective-communication-cultural-competence-and-patient--and-family-centered-care-across-the-care-continuum/>.
- <sup>163</sup> Health Research & Educational Trust, American Hospital Association. *Patient and Family Engagement Survey*. Chicago, IL: Health Research & Educational Trust [http://www.hret.org/quality/projects/resources/more\\_foundation\\_patient\\_family\\_engagement\\_survey.pdf](http://www.hret.org/quality/projects/resources/more_foundation_patient_family_engagement_survey.pdf).
- <sup>164</sup> Institute for Patient- and Family-Centered Care. *Better Together - Partnering with Patients and Families: Organizational Self-Assessment*. Bethesda, MD: Institute for Patient- and Family-Centered Care [https://www.cfhi-fcass.ca/sf-docs/default-source/patient-engagement/better-together-organizational-self-assessment\\_eng.pdf?sfvrsn=2](https://www.cfhi-fcass.ca/sf-docs/default-source/patient-engagement/better-together-organizational-self-assessment_eng.pdf?sfvrsn=2).
- <sup>165</sup> Alberta Health Services: Patient Engagement. *A Resource Toolkit for Engaging Patient and Families at the Planning Table*. Edmonton, AB: Alberta Health Services <http://www.albertahealthservices.ca/assets/info/pf/if-pf-pe-engage-toolkit.pdf>.
- <sup>166</sup> Sprague D, Young S, Jones A. How Healthy Is Your Patient and Family Advisory Council? Presented at the: International Conference on Patient and Family-Centered Care; July 27, 2016; New York, NY.
- <sup>167</sup> The Change Foundation. *Charting a New PATH*. Toronto, ON: The Change Foundation; 2016. <http://www.changefoundation.ca/charting-a-new-path/>.
- <sup>168</sup> Herrin J, Harris KG, Kenward K, Hines S, Joshi MS, Frosch DL. Patient and family engagement: A survey of US hospital practices. *BMJ Qual Amp Saf*. 2016;25(3):182. doi:10.1136/bmjqs-2015-004006
- <sup>169</sup> Abelson J, Humphrey A, Syrowatka, Bidonde J, Judd M. Evaluating Patient, Family and Public Engagement in Health Services Improvement and System Redesign. *Healthc Q*. 2018;21(Special Issue):31-37.